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Is a family-centred initiative a family-centred service? A case of a Conductive Education setting for children with cerebral palsy

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Abstract

Background From the moment a child is diagnosed as having cerebral palsy, families have to cope on a daily basis with the multifaceted challenges of life-long disability management. Family-centred service is embraced as a 'best practice' model because of accumulating evidence supporting its positive influence on parents and children's outcomes. Nevertheless, research comparing parent and provider perspectives on family-centred practices of educational service providers in education settings is scarce. The aims of this study were to compare the extent to which parents and conductors experience the service delivery in *Tsad Kadima*, the Association for Conductive Education in Israel, as being family-centred, as well as comparing parents' perception of different educational settings as being family-centred.

Methods Measurements of family-centeredness, the Israeli Measure of Processes of Care for families (MPOC-20) and for service providers (MPOC-SP), were administrated to 38 teacher conductors and 83 families of children with cerebral palsy (aged 1–14), from different conductive educational settings. Results Parents and conductors perceive Conductive Education service as being highly family centred in most domains, rating respectful and supportive care the highest and providing general information the lowest, thus indicating an area where improvements should be made. Parents perceived the service they receive to be more family-centred than conductor's perception about their own activities. In addition, educational setting (day care, pre-school and school) was found to be associated with parent's scores.

Conclusions The current study, which is the first to examine family-centred service provision in a conductive special education setting, from the perspectives of both parents and conductors, provides significant evidence for high-quality services in these settings.

Keywords

cerebral palsy, familycentred service, Conductive Education, MPOC-20, MPOC-SP, educational

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Introduction

Cerebral palsy (CP) is a life-long developmental condition with reported prevalence of around 2–2.5 per 1000 live births in

developed countries (Surveillance of Cerebral Palsy in Europe 2000). The current definition of CP (Rosenbaum *et al.* 2007) highlights the impact of the condition on a child's development and functioning. However, children with CP never

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present on their own. From the moment a child is diagnosed as having CP, a 'new' family is born, a family whose responsibility is now to cope with the multifaceted challenges associated with management of a life-long impairment. This perspective, supported by the International Classification of Functioning, Disability and Health framework (WHO 2001), obliges us to expand our view and include the child's immediate and most essential environment – their family (Rosenbaum 2007; 2008).

The term family-centred service (FCS) refers to an approach to service delivery characterized by practices that treat families with dignity and respect, provide information sharing, encourage family choice regarding involvement in and provision of services and promote parent-professional partnerships as the context for family programme relations (Shelton & Stepanek 1995; Rosenbaum et al. 1998; Dunst 2002; King & Chiarello 2014). This approach empowers families to become the directors of their child's life, emphasizes child and family strengths and provides them with the best available information and perspectives on issues they identify as important (Espe-Sherwindt 2008; Rosenbaum & Rosenbloom 2012). As such, FCS is embraced as the foundational approach to service delivery and has been considered as a 'best practice' model. Accumulated evidence support the efficacy of this model and its positive influence on parents and children's outcomes (Cunningham & Rosenbaum 2014; King & Chiarello 2014). Studies which evaluate familycenteredness of services have been performed with reliable and valid tools such as the Measure of Processes of Care for families (MPOC-56 and MPOC-20) (King et al. 1996, 2004) and for service providers (MPOC-SP) (Woodside et al. 2001). However, few studies have linked parent and provider perspectives on family-centred practices (Cunningham & Rosenbaum 2014). Such correlation is important if we want to determine the overall quality of services. Studies examining service providers and families in education settings, as distinct from hospitals and rehabilitation centres, are also scarce (Mazer et al. 2006; Jeglinsky et al. 2011a, 2011b; Tang et al. 2012).

Conductive Education (CE), developed originally in Hungary by András Petö and followers, is a comprehensive educational system for raising and educating children and adults with physical disabilities. Its underlying premise is that children's development and learning are distorted because of the effects of the manifestations of neurological impairment upon body function and through this, upon individuals' transactions with the social and material environments, through which learning and development occur. This counterproductive learning process may lead to

the development of non-use at the physical level and learned helplessness at the psycho-social level and may restrict children's ability to adapt to changing environmental conditions and become active participating autonomous persons (Sutton 1988; Kozma 1995; Bourke-Taylor et al. 2007; Feuerstein 2008; Schenker et al. 2010; Lotan et al. 2012). Based on the belief that child development is active, reciprocal and transformative in nature if provided with appropriate learning conditions, CE offers a unified process of teaching and learning that merges the various developmental domains (e.g. emotional, cognitive, motor and communicative) through a unique integrative pedagogy of social and psychological mediation (conductive pedagogy), led by a broadly trained teacher specialist known as a 'conductor', in an appropriate organizational structure. Tsad Kadima (TK – Hebrew for 'a step forward'), the Association for CE in Israel, was established in 1987 as a collaborative educational initiative of parents and professionals and provides conductive services to children and adults with CP in educational and community settings nationwide. FCS is the philosophy that underpins the practice referred to as family-centred conductive service. The Israeli model of CE intertwines the conductor's unified panoramic perspective of human learning processes with the disciplinary knowledge of health and welfare professionals into a transdisciplinary integrative practice. As the prime worker in the team around the child, the conductor is the main figure to collaborate with parents.

As part of a quality assurance process, and together with the increased demand from services to show evidence of the usefulness of practices, the aims of this exploratory study were as follows:

- 1 to compare the extent to which parents and conductors experience the service delivery in TK as being family-centred;
- 2 to compare parents perceived family-centeredness according to setting (day care, pre-school and school); and
- 3 to identify strengths and gaps in FCS provision to determine specific areas for improvement.

Before performing the analysis we hypothesized that (1) parents and conductors perceive TK as being family-centred; (2) parents' perceptions of FCS will not differ significantly from those of conductors; (3) parents' perceptions of FCS will differ significantly based on the child's setting, such that parents of children in day care will report a more positive perception of FCS than parents of children in pre-school and

school settings; and (4) both parents and conductors will experience 'treating people respectfully' as an area of strength and 'providing general information' as an area of weakness.

Methods

Participants

Eighty three (42%) of 197 families of children registered in TK's conductive special education setting returned the MPOC-20 questionnaire. The response rate of conductors was much higher with all 38 (100%) returning the MPOC-SP questionnaire. Of the 83 parents, 24 (29%) had toddlers in day care classes (1-3 years), 40 (48%) had children in pre-school (3-6) and 19 (23%) had school aged children (7-14).

Instruments

Two measures of family-centeredness were administrated: the MPOC-20 (King et al. 2004) and the MPOC-SP (Woodside et al. 2001). MPOC-20 is a 20-item self-administered questionnaire to capture parents'/caregivers' perceptions/experiences of 'the extent to which' professionals' practices reflect FCS behaviours. These items group into five domains: Enabling and Partnership, Providing General Information, Providing Specific Information, Co-ordinated and Comprehensive Care, and Respectful and Supportive Care. MPOC-20 uses a rating scale that ranges from 1 to 7 (1 = 'not at all', 4 = 'to a moderate extent' and 7 = 'to a very great extent'), with higher scores reflecting more familycentred behaviours. MPOC-20 is psychometrically sound with good internal consistency for the five scales (Cronbach's alphas ranging from 0.83 to 0.90), and moderate to high intercorrelations among five scale scores ranged from 0.56 to 0.87; high test-retest reliability (intra-class correlation coefficients ranging from 0.81 to 0.86), and good concurrent validity with significant positive correlations with a measure of satisfaction, and negative with a single-item stress variable (King et al. 2004). It has been recommended for use in quality assurance and programme evaluation activities and has the advantage of being quick to complete.

MPOC-SP is an analogue of MPOC-20 consisting of a 27item self-assessment questionnaire for professionals to selfreport their practices with respect to family-centeredness. These items group into four domains: Showing Interpersonal Sensitivity, Providing General Information, Communicating Specific Information about the Child and Treating People Respectfully. The same 7-point rating is used as in MPOC-20. MPOC-SP scales have good test-retest reliability (intra-class correlation coefficients ranging from 0.79 to 0.99), good internal consistency (Cronbach's alphas ranging from 0.76 to 0.88) and is a discriminating measure of professional caregiving behaviours (Woodside et al. 2001).

MPOC-20 and MPOC-SP were translated into Hebrew with permission of the developers, followed by standardized procedures required for back-translation. The cultural adaptability of the MPOCs to Israeli context was discussed in a multidisciplinary group of experts following the translational approval. The content was discussed in relation to different Israeli practices to ensure their relevance and applicability to potential users and was found to be culturally adaptable. To confirm the internal consistency of the Israeli version, Cronbach's alpha coefficients were calculated and found to be good for each of the five scales of the MPOC-20 (0.75-0.92) and the four scales of MPOC-SP (0.65-0.89). In addition, correlations between the domains within each tool were calculated. The five MPOC-20 domains correlated between 0.44 and 0.88, and the four MPOC-SP domains between 0.22 and 0.71, confirming that each domain addresses a distinct facet of family-centred practice and thus the construct validity of the Israeli MPOCs.

Procedure

Following approval from the Ethical Committee of the Association for Conductive Education in Israel, Tsad Kadima (ECCETK), parents and conductors received a written invitation from the chief researcher (RS) to participate in the study describing its purpose, and a blank copy of MPOC-20 or MPOC-SP. As approved by the ECCETK, consent was indicated by the submission of the questionnaires. Participants sent the questionnaire back to the setting's secretariat that transferred it anonymously to the chief researcher. As return packages were anonymous, an effort was made to optimize response rates by sending two reminder letters to all participants, the first after two weeks and the second, with the same questionnaires, after a month. No identifying information was requested beyond indicating whether the child studied in a preschool or school setting.

Statistical analysis

Data were recorded using the syntax codes described by CanChild (Woodside et al. 2001; King et al. 2004). One-way ANOVA was used to test the relationship between educational settings and MPOC-20 scores. Mixed repeated measures ANOVA, applying Greenhouse–Geiser correction for violation of sphericity, was used to test for mean group differences between parents and conductors on four matched domain scores on the basis of conceptual underpinning of the MPOC (Bellin *et al.* 2011). The main analyses of both ANOVAs were followed by post-hoc simple effects analysis applying Bonferroni correction for multiple comparisons. All comparisons were two-sided, and a *p*-value of 0.05 was considered to indicate statistical significance. All analyses were carried out using IBM-SPSS 20.

Results

Descriptive statistics of both measurements' domains are presented in Table 1. All domains, except MPOC-SP's 'Showing interpersonal sensitivity', yielded good reliability coefficients ranging between $\alpha = 0.74$ and $\alpha = 0.92$. The scale scores and total scores of the two measures showed a consistent pattern of higher scores for MPOC-20 scale.

To explore the differences between parents and conductors' perceptions, a mixed repeated-measures ANOVA was performed. Table 2 presents the comparable domains between both questionnaires, as suggested by Bellin *et al* (2011).

These domains served as the within factor, while questionnaire type (MPOC-20, MPOC-SP) served as the between factor. The results of the analysis are presented in Fig. 1. The analysis revealed significant main effects for the following domains: 'respectful and supportive care', 'providing specific information', enabling and partnership and providing general information [$F_{(2.06,244.86)} = 79.03$, P < 0.001] and questionnaire (MPOC or MPOC-SP) [$F_{(1,119)} = 11.26$, P = 0.001]. The interaction effect, however, was not significant [$F_{(2.06,244.86)} = 2.35$, P = 0.1]. The post-hoc analysis revealed that in the

Table 2. Comparable domains between the MPOC-20 and the MPOC-SP

MPOC-20 domains	Comparable MPOC-SP domains		
Enabling and partnership	Showing interpersonal sensitivity		
Respectful and supportive care	Treating people respectfully		
Providing specific information Providing general information	Communicating specific information Providing general information		

Abbreviations: MPOC, Measure of Process of Care; SP, service provider.

questionnaires the *Respectful and supportive care* domain yielded significantly higher scores and the *Providing general information* domain yielded significantly lower scores, compared with the other domains. In addition, all domain scores, apart from *Respectful and supportive care*, were significantly higher in the parent-reported MPOC-20 compared with the conductor-reported MPOC-SP, indicating that parents perceived the service they receive to be more family-centred than conductors feel about their own activities.

In order to explore the relationship between parents' scores and children's educational setting (day care, pre-school or school), a one-way ANOVA was performed. The analysis revealed a main effect for educational setting for two of the five MPOC-20 domains: *Enabling and partnership* and 'Coordinated and comprehensive care' (Table 3). Post-hoc analysis revealed that these effects stemmed mainly from the higher scores of parents whose children attend school, indicating perceptions of better FCS by these parents, compared with parents of day care and pre-school setting.

To identify areas for improvement, the measures' developers recommend identifying those items of which at least 33% of the respondents scored 4 ('sometime') or less. Frequency distributions are presented in Table 4. All items but one (number 9) belong to the domain *Providing general information*.

Table 1. Descriptive statistics of the MPOC-20 and MPOC-SP domains

Questionnaire	Index	No. of items	Mean	SD	Median	Cronbach o
MPOC-20 (n = 83)	Respectful and supportive care	5	6.39	0.76	6.60	0.84
	Providing specific information	3	6.06	0.98	6.06	0.75
	Enabling and partnership	3	5.94	0.99	6.00	0.81
	Providing general information	5	5.17	1.32	5.40	0.80
	Co-ordinated and comprehensive care	4	6.10	0.91	6.50	0.78
	Total score	20	5.91	0.82	6.10	0.92
MPOC-SP (<i>n</i> = 38)	Showing interpersonal sensitivity	10	5.36	0.57	5.45	0.65
	Treating people respectfully	9	6.14	0.53	6.11	0.74
	Communicating specific information about the child	3	5.60	0.91	5.67	0.76
	Providing general information	5	4.42	1.31	4.50	0.88
	Total score	27	5.48	0.59	5.52	0.89

Abbreviations: MPOC, Measure of Process of Care; SP, service provider; SD, standard deviation.

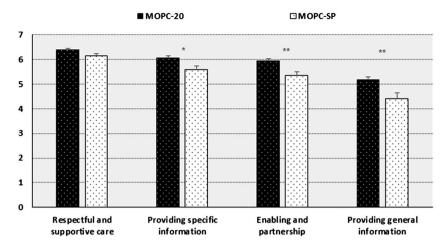


Figure 1. Comparison between MPOC-20 and MPOC-SP domains.

Table 3. Differences in MPOC-20 domains by children's educational settings.

	Day care	Pre-school	School	F _(2,81)	Omnibus <i>p</i> -value
E&P (M \pm SD, SE) †	6.07 ± 1.06, 0.22	5.69 ± 1.00, 0.16	6.40 ± 0.59, 0.14	3.89	0.03
CCC (M \pm SD, SE) †	$6.00 \pm 1.04, 0.22$	$5.89 \pm 0.90, 0.14$	6.71 ± 0.34 , 0.08	6.24	0.003
TS (M ± SD,SE) §	$5.88 \pm 0.93, 0.19$	$5.73 \pm 0.78, \ 0.12$	6.83 ± 0.54 , 0.12	4.52	0.01

Abbreviations: M, mean; SD, standard deviation; SE, standard error of the mean; E&P, enabling and partnership; CCC, co-ordinated and comprehensive care; TS, total score post-hoc comparisons.

Discussion

Family-centred practice is by nature a transactional process of care, depending as much on service providers' perceptions as on those of families, and on their collaboration. Transaction implies an ongoing process of mutual and emergent effects within relationships which are transformative (Fogel 2009). 'Transactions are omnipresent. Everyone in the universe is affecting another or being affected by another. Everything is in a relationship, from the most complex society to the most elementary particle' (Sameroff 2009, p.3). With that perception in mind, the main aim of this study was to capture complementary perspectives of family-centred care from both parents and conductors.

To date, only 10 papers have examined parents and service providers' perceptions regarding the delivery of FCS, of which only five used the MPOC-20 and MPOC-SP (Cunningham & Rosenbaum 2014, Stefánsdóttir & Thóra Egilson 2015). Most studies were performed in medical settings (e.g. hospitals and rehabilitation centres), among health professionals and families of children with neurodevelopmental disabilities (Raghavendra et al. 2007; Bellin et al. 2011; Dickens et al. 2011; Jeglinsky et al. 2011b, Jeglinsky et al. 2011a; Stefánsdóttir & Thóra Egilson 2015). To the best of our knowledge, the current study is the first to examine FCS provision in a conductive special education setting, from the perspectives of both parents and conductors.

As hypothesized, our findings suggest that conductors are perceived by parents as doing very well in providing care that is respectful and supportive, co-ordinated and comprehensive and that enables partnerships. A similar perception has been observed among the conductors themselves. Yet, unlike our hypothesis, our study revealed that all MPOC-20 scale scores (besides that of Respectful and supportive care) were significantly higher compared with those of the conductors, indicating that parents perceived the service to be more family-centred than conductors perceive that they are delivering it. This finding is not in line with most studies

[†] The school group score was significantly higher than the kindergarten group score (P = 0.03).

[‡] The school group score was significantly higher than the kindergarten and pre-kindergarten day care groups scores (P = 0.003; P = 0.03, respectively).

[§] The school group score was significantly higher than the kindergarten group score (P = 0.01).

Table 4. MPOC-20 and MPOC-SP items that 33% or more of respondents identified as occurring only 'to a moderate extent' or less

Questionnaire	ionnaire Item no. Item content		Index	n, %	
MPOC-20	16	Give you information about the types of services offered at the organization or in your community?	PGI	31, 37%	
	17	Have information available about your child's disability?	PGI	29, 35%	
	19	Have information available to you in various forms?	PGI	35, 43%	
MPOC-SP	9	Anticipate parents' concerns by offering information even before they ask?	SIS	16, 42%	
	23	Promote family-to-family 'connections' for social, informational or shared experiences?	PGI	22, 60%	
	25	Provide advice on how to obtain information or to contact other parents?	PGI	16, 42%	
26	26	Provide opportunities for the entire family, including siblings, to obtain information?	PGI	23, 61%	
	27	Have general information available about different concerns?	PGI	24, 63%	

Abbreviations: MPOC, Measure of Process of Care; SP, service provider.

of cross-informant agreement, where no significant differences emerged (e.g. Dyke *et al.* 2006; Raghavendra *et al.* 2007; Bellin *et al.* 2011; Dickens *et al.* 2011). This suggests that conductors are perhaps more critical than parents about the quality of care they provide. This critical perspective is indeed positive and may prod conductors into taking measures to improve the quality of care.

A surprising finding was the association between children's educational setting (day care/ pre-school/school) and parents' scores. Scores were high in the day care setting, were lower in pre-school (though not significantly) and were higher again in school. In other studies, mean scores of most domains of the MPOC-20 decrease as age increases (Granat et al. 2002; Bjerre et al. 2004; Dyke et al. 2006; Raghavendra et al. 2007; Fingerhut et al. 2013). While higher scores in early intervention years are not surprising, our findings are intriguing and do not meet our hypothesis. One possible explanation may be that when children move from early childhood services into school-aged services, there is a reduced contact with therapists. This is, however, not the case in education-based services, where educational staff accompanies the family throughout their child's development. One should also note that while in other studies differences between age groups were measured, in this study differences were measured between educational settings within the same centre, where conductors accompany children and families in different stages and transitions. We believe that parents of school-age children are in need of the same behaviours of care as parents of young children and appreciate them in the long run.

As in most studies using the MPOC measures (MPOC-SP, MPOC-56 and MPOC-20) (for review see Cunningham & Rosenbaum 2014), our findings revealed that conductors tended to agree with families regarding which features of FCS were most prominent in their practices. Both conductors and parents rated *treating people respectfully* the

highest and providing general information the lowest. This is an interesting finding as it implies that the context/setting where FCS is provided perhaps has no important effect on service delivery. One possible explanation for conductors scoring relatively low in this domain may be that providing general information in a multidisciplinary special education system is often the primary responsibility of the social worker. This explanation is supported by Woodside et al (2001), Raghavendra et al (2007) and Jeglinsky et al. (2011b), where higher scores were given by social workers and psychologists in this domain. Another explanation for what seems to be a universal finding may be that service providers have significant demands placed on them and often have little time available with each family to discuss general information (Cunningham & Rosenbaum, 2014). On the other hand treating people respectfully is perceived as a basic positive attitude of service delivery that is expected from service providers and is well provided.

When comparing our MPOC scores to those of other studies (Dyke et al. 2006; Nijhuis et al. 2007; Raghavendra et al. 2007; Siebes, et al. 2007; Camden, et al. 2010; Hagen& Bjorbaekmo 2010; Bellin et al. 2011; Dickens et al. 2011; Jeglinsky et al. 2011b; Jeglinsky et al. 2011a; Arnadottir & Egilson 2012; Himuro, et al. 2015), parents and conductors' scores were higher in all domains with smaller standard deviations. It may well be that being a family-professional partnership-based programme, TK offers high-level FCSs. Furthermore, as family-centred care is included in the Israeli conductors' training curricula both theoretically and practically, they might internalize the important role of the family in the child's development and the powerful effect of parent-professional partnerships while being socialized to the profession (Sewell 2012). Tang et al. (2012) argue that teachers usually spend more time working with parents and children than health professionals and therefore are more accessible to parents. It is obvious that more in-depth

research is needed in order to explore other variables in TK's framework that might further explain these observed patterns.

Another aim of this study was to identify areas where improvements could be made. Only a few gaps in service delivery were identified, specifically in the domain of providing general information. Among parents, 37-43% identified three of 20 items of the MPOC-20 that occurred sometimes or less and 42-63% of conductors identified four of 27 items of the MPOC-SP that occurred sometimes or less. These items were also identified as weak points in various studies (Dyke et al. 2006; Camden et al. 2010; Bellin et al. 2011; Jeglinsky et al. 2011a, 2011b; Wang et al. 2014), yet in other studies, additional domains were also identified as needing improvement. The fact that parents identified these items as relative weakness in TK's service provision should be further investigated, and steps should be taken to explore ways to improve service provision in this specific domain.

A limitation of this study was the relatively low response rate of families. It is therefore not possible to rule out selection bias, because families who participated may have had more favourable experiences with FCS. There is also a potential recall or social desirability bias.

In conclusion, TK is perceived and experienced by parents and conductors as family-centred. Overall, this study adds to the relatively limited 'panoramic' accumulative knowledge on both parents and professionals' perceptions of FCS and to the emerging research in validating the usefulness of the MPOC tools in contexts that are different from the ones it was originally developed for (King et al.1996). Above all, it is the first study to evaluate the quality of service delivery in a special education conductive framework and of conductors as service providers.

Our findings confirm that TK's culture and climate are family-centred. As family-centeredness is linked to better outcomes for children and better parent well-being (Cunningham & Rosenbaum 2014; King & Chiarello 2014), these findings are important for providing high-quality evidencebased services.

Further research would benefit from in-depth qualitative exploration of the 'general information' construct as understood by families and professionals. In addition, studies of FCS provision should be performed in other educational environments and include other professionals working with parents in special and inclusive education systems.

Key Messages

- · The International Classification of Functioning, Disability and Health provides a framework for thinking about family-centred services.
- · Perceptions regarding family-centred care from both parents and service providers are important in determining the overall quality of services.
- Conductors are highly qualified in providing familycentred -service to families of children with CP.
- · The MPOCs are useful in an educational setting even though they were originally developed for medical rehabilitation.

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