Parents’ perceptions of the services provided to children with cerebral palsy in the transition from preschool rehabilitation to school-based services

M. W. Alsem,* M. Verhoef,* J. W. Gorter,† L. C. M. Langezaal,* J. M. A. Visser-Meily* and M. Ketelaar*

*Brain Centre Rudolf Magnus and Centre of Excellence for Rehabilitation Medicine, De Hoogstraat Rehabilitation and University Medical Centre Utrecht, Utrecht, The Netherlands, and
†Department of Pediatrics and CanChild Centre for Childhood Disability Research, McMaster University, Hamilton, Canada

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Summary

Aim To describe the course of parents’ perceptions of the family centredness of rehabilitation services provided to their children with cerebral palsy (CP) before and after the transition from preschool to school-based services.

Background Parents of 59 children with CP aged 2.5 to 4.5 years filled in the 56-item Measure of Processes of Care (MPOC-56) on three occasions pre (2) and post (1) transition to school-based services. Friedman tests were used to describe changes in parents’ perceptions over time. Mann–Whitney U tests were used to describe differences in course of parents’ perceptions between regular school and special school or day care.

Results Parents’ perceptions of preschool services were stable between the ages of 2.5 and 3.5 years, with a decline after transition on four of the five domains of the MPOC ($P < 0.05$). The domain providing general information was scored lowest (median at baseline 3.56, IQR 2.39) compared with the four other MPOC domains, but remained stable over time. No differences in course of parental perceptions were found for school type.

Conclusion The transition from preschool to school-based services for children with CP is associated with a decrease in parents’ perception of family-centred practices.

Introduction

In 1998, Rosenbaum defined the term family-centred services (FCS) as ‘[…] a set of values, attitudes, and approaches to services for children with special needs and their families. Family-centred services recognizes that each family is unique, that the family is the constant in the child’s life, and that [parents] are the experts on the child’s abilities and needs. The family works together with service providers to make informed decisions about the services and support the child and family receive. […]’ (Rosenbaum et al. 1998).

Although the concepts of FCS have been around for more than four decades (Bamm & Rosenbaum 2008), and the principles of family-centred theories have been widely described and promoted (Rosenbaum et al. 1998; Turnbull et al. 2000; S. King et al. 2004; MacKean et al. 2005; Bamm & Rosenbaum 2008; Moore et al. 2009; Darrah et al. 2012), full implementation of these concepts is difficult to achieve (Bailey et al. 2012). Moreover, longitudinal evaluation of parents’ perception of FCS is scarce (Cunningham & Rosenbaum 2013), and the effects on child outcomes are uncertain (Bailey et al. 2012), making it hard to truly
understand the role of FCS and the effect on FCS on clinical outcomes.

From recent paediatric rehabilitation literature, however, we have learned that interventions focusing on both children and families lead to satisfaction with care, parent’s well-being and reduced parental stress (King et al. 2004; Bamm & Rosenbaum 2008; Rosenbaum & Gorter 2012).

The role of parents in the healthcare process and healthcare professional behaviours is essential to understand the processes of care. The large individual differences and changes in time make these attributes difficult to assess in daily practice (Feldman et al. 1999; MacKean et al. 2005; Bamm & Rosenbaum 2008). This unique character, together with the changing nature of family needs and parental involvement, makes delivering family-centred services a dynamic process, in which the roles of parents and therapists change over time. These roles should be defined on the basis of true collaboration and open communication between parents and therapists. Because the degree of family centrness demanded by parents depends on individual differences and is changing over time, it should be established regularly and should not be defined by the therapist (MacKean et al. 2005).

In the Netherlands, each year, 14 000 children are treated in specialized rehabilitation programs in a rehabilitation centre or hospital (Revalidatie Nederland 2012). About 40–50% of the treated children are diagnosed with cerebral palsy (CP) (Revalidatie Nederland 2012). After neurological evaluation, young children with CP are mostly referred to rehabilitation services for support and therapy. Therapy is provided in different settings and intensities, depending on the child’s and families’ needs (Siebes et al. 2007a). Whereas the intensity of therapy and the therapists may change, parents are the constant factor, and they will be involved in their child’s therapy across settings. This is important during the transition to school, in which parents play a key role in making choices.

In The Netherlands, most children start attending school at the age of four. At that age, children will attend either a mainstream school with or without rehabilitation services, special schools with integrated rehabilitation programs for children with disabilities or specialized day care programs. Going to school is a major life event in young children (Brown & Cowen 1988; Darrah et al. 2012), especially for those with CP (Arnaud et al. 2008). In this new environment, other therapists may be involved, the focus of therapies could change, and certain therapies may be given at school instead of home or in the rehabilitation setting (Darrah et al. 2012). The integration of therapies in learning situations and the balance between therapy and school might be different between regular and specialized schools or day care programs (Nijhuis et al. 2007). For example, parents are less often present at therapy when it is given at school. The experience with children with CP might also differ between mainstream schools and specialized centres. These changes in environment may have an effect on the parental perception of the services they and their child receive (Rous et al. 2010).

In the context of the changing degree of involvement of professionals and parents, it is essential to understand how these services are actually perceived by those who receive them (S. King et al. 2004), and how this perception changes over time, especially in periods of transition between the preschool and school setting. Similar to other transitions, either age-defined or system-defined knowledge about perceptions of services before and after transition creates awareness and could help in preparing both parents and professionals for the changes in services (Nijhuis et al. 2007).

The most widely used instrument to measure parents’ perception of FCS in paediatric settings is the Measure of Processes of Care (MPOC) (S. M. King et al. 1996; Cunningham & Rosenbaum 2013). The MPOC is a self-reported measure of parents’ perception of the amount to which specific behaviours of healthcare professionals occur (S. M. King et al. 1996), and is associated with the age of children. Parents of preschool-aged (younger than 6 years) children with CP in Australia had higher MPOC scores than parents of older children with CP (Dyke et al. 2006). However, these data are cross sectional, and no conclusions can be drawn to changes in appreciation of FCS in individual cases.

Today, only four studies used the MPOC-56 to measure changes over time (Rahi et al. 2004; Legrow & Rossen 2005; Siebes et al. 2007b; Camden et al. 2010; Cunningham & Rosenbaum 2013). Three of these studies are intervention studies, and one measures the stability of the instrument over 1 year. These studies do not describe the ‘natural course’ of parental perception of services over transition periods. Hodgetts et al. (2013) described the provision of FCS across different service sectors quantitatively using the MPOC, as well as qualitatively, and conclude that there is no difference on experiences of FCS between these sectors.

A recent review concludes that in general, studies that use the MPOC report a good provision of FCS (Cunningham & Rosenbaum 2013). However, most studies report that the domains providing general and specific information about the child are mostly scored lowest by parents, also in parents of children with CP (Jeglinsky et al. 2012). This means that parents feel that they are not sufficiently informed, suggesting an area for improvement of FCS. This has been confirmed by
other, most qualitative studies, on the provision of information to parents (Pain 1999; Hummelinck & Pollock 2006).

The aim of this study is to describe the course of parents’ perceptions of the family-centredness of the care they and their young children with CP receive in the transition from preschool rehabilitation programs to school-based services.

**Method**

**Participants**

This study is part of the longitudinal prospective research program entitled Pediatric Rehabilitation Research in the Netherlands – Cerebral Palsy (PERRIN, www.perrin.nl), in which children with CP and their parents were followed to examine the course and determinants of functional status, participation and quality of life. In the PERRIN CP 0–5 study, the focus is on the development of young children with CP, starting at the age of 18 months and followed till 4.5 years. Between April and December 2005, parents of children with CP, in five hospitals and six rehabilitation centres, were asked by either their treating paediatrician, child neurologist or rehabilitation physician, whether they were willing to participate in the PERRIN CP 0–5 study.

The inclusion criteria were the age of 1.5 or 2.5 years, and CP diagnosed by a physician and confirmed by a paediatric physiatrist. The exclusion criteria were children having a condition besides CP affecting motor functioning, and children of parents with a weak command of Dutch language. All children participating in this study received regular care covered by the standard Dutch healthcare insurance, including rehabilitation services such as physical and occupational therapies.

The Medical Ethics Committee of the University Medical Centre Utrecht and all participating centres approved the study.

**Procedures**

All children and their families were assessed in a series of annual assessments at the age of 2.5 years (time 1), 3.5 years (time 2) and shortly after the transition from preschool to school at the age of 4.5 years (time 3). Research assistants determined the children’s Gross Motor Function Classification System levels (Palisano et al. 1997), type of CP and distribution (Rosenbaum et al. 2007) and type of school attended at the age of 4.5 (mainstream school with or without special needs support, special education or day care). The parents were asked to complete a questionnaire booklet including the 56-item MPOC-56, Dutch version (van Schie et al. 2004) prior to their visit to the centre.

**Measure of processes of care**

The MPOC-56 is a self-administered questionnaire consisting of 56 items that was designed to find out what parents of children (0 to 17 years old) with chronic health problems think of the services they and their child receive, and to measure the extent of the family centredness of the rehabilitation services (S. King et al. 1995; S. M. King et al. 1996). The MPOC is administered by the primary caregiver of the child.

For each item, the parents respond to a common question: ‘to what extent do people who work with your child…’, followed by an item describing a specific action or behaviour of healthcare professionals or rehabilitation staff. The final 11 questions of the MPOC-56 ask about the centre where the child receives services, instead of the professionals in the team. All questions refer to the behaviours of the rehabilitation team or centre occurring during the past year.

The items are scored on a seven-point Likert scale, with 7 indicating that the service provider engaged in this behaviour ‘to a very great extent’, and 1 indicating ‘never’. A score of 0 indicates that the item is ‘not applicable’. Scale scores on five scales are then calculated by averaging the items in that scale, following the instructions of the MPOC manual (S. King et al. 1995). The scales are (1) enabling and partnership (16 items) – reflecting parents’ involvement in the care process, particularly in decision-making; (2) providing general information (nine items) – activities that meet parents’ general information needs; (3) providing specific information about the child (five items) – behaviours by which parents are provided with information about their own child; (4) co-ordinated and comprehensive care for child and family (17 items) – care of the whole child and family, and care that is continuous and consistent over time, settings and people; and (5) respectful and supportive care (nine items) – care in which parents are treated with respect as individuals, equals and experts about their child. The Dutch MPOC-56 is a validated translation of the Canadian MPOC-56 (van Schie et al. 2004). Both have sound psychometric properties. Test–retest reliabilities (intraclass correlation coefficients) range from 0.80 and 0.79 (providing general information) to 0.88 and 0.94 (enabling and partnership) for the five scales of the Canadian and Dutch studies, respectively (S. M. King et al. 1996; van Schie et al. 2004).

**Statistical analysis**

The data were entered into the Statistical Package for the Social Science (version 19.0). Descriptive statistics were run to
explore the demographic variables. The level for detecting statistical significance (alpha) was set at 0.05.

The MPOC scale scores were computed using the procedures prescribed by King and colleagues, by calculating the averages of the item’s ratings for valid questionnaires and scales (S. King et al. 1995). The differences in numbers between scales are caused by the inability to calculate the scale scores due to missing items. For each scale, we used the data of the children who had a valid scale score at all three ages for that particular scale. To rule out selective dropout, various child characteristics of responders and non-responders were compared with a $\chi^2$-test.

The course of the MPOC scale scores of the children between time 1, 2 and 3 was described at group level by analysing the changes in median scale scores using Friedman tests. If there was a statistically significant change, post-hoc tests using Wilcoxon signed rank tests were conducted to test the significant differences between times (i.e. ages). To see whether there is a difference in the course of perceived FCS between regular school and special education or day care centre, we analysed the differences in the changes of MPOC scores between the two groups using Mann–Whitney U tests.

### Results

#### Participants

A total of 100 children with CP were included at the age of 2.5 years (Fig. 1). At follow-up, three children did not meet the criteria for CP (they later appeared to have other conditions or diagnoses). Further, there was a dropout of five children and their parents because of the study’s burden for the child or the family.

Of the 92 children eligible for further analysis, ten parents did not fill out the MPOC questionnaire at any of the measurement occasions, and from 23 parents, the MPOC data of only one of the measurement occasions was available. Thus, the data of 59 children were used for analysis. These children all had complete data at all three time points. To rule out selective dropout, the characteristics of the children in the

### Table 1. Study population at the age of 2.5 years

<table>
<thead>
<tr>
<th>Child characteristics</th>
<th>Total inclusion</th>
<th>Eligible for analysis</th>
<th>Difference between analysed group and dropout?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Boy</td>
<td>54 (58.7)</td>
<td>35 (59.3)</td>
<td></td>
</tr>
<tr>
<td>Girl</td>
<td>38 (41.3)</td>
<td>24 (40.7)</td>
<td></td>
</tr>
<tr>
<td><strong>Type of CP</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spastic bilateral</td>
<td>49 (53.2)</td>
<td>31 (52.5)</td>
<td></td>
</tr>
<tr>
<td>Spastic unilateral</td>
<td>40 (43.5)</td>
<td>26 (44.1)</td>
<td></td>
</tr>
<tr>
<td>Dyskinetic</td>
<td>2 (2.2)</td>
<td>2 (3.4)</td>
<td></td>
</tr>
<tr>
<td>Mixed</td>
<td>1 (1.1)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td><strong>GMFCS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>28 (30.4)</td>
<td>17 (28.8)</td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>12 (13.0)</td>
<td>8 (13.6)</td>
<td></td>
</tr>
<tr>
<td>III</td>
<td>23 (25.0)</td>
<td>16 (27.1)</td>
<td></td>
</tr>
<tr>
<td>IV</td>
<td>20 (21.8)</td>
<td>15 (25.4)</td>
<td></td>
</tr>
<tr>
<td>V</td>
<td>9 (9.8)</td>
<td>3 (5.1)</td>
<td></td>
</tr>
<tr>
<td><strong>School type at the age of 4.5</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regular</td>
<td>18 (19.6)</td>
<td>14 (23.7)</td>
<td></td>
</tr>
<tr>
<td>Regular with SNS</td>
<td>11 (11.9)</td>
<td>7 (11.9)</td>
<td></td>
</tr>
<tr>
<td>Special education</td>
<td>42 (45.7)</td>
<td>32 (54.2)</td>
<td></td>
</tr>
<tr>
<td>Specialized day care</td>
<td>5 (5.4)</td>
<td>5 (8.5)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>16 (17.4)</td>
<td>1 (1.7)</td>
<td></td>
</tr>
</tbody>
</table>

CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; SNS, special needs support; ns, not significant.

*Using $\chi^2$-tests.
group that was not included in the analysis and the characteristics of the ‘eligible for analysis’ group were compared. No significant differences were found (Table 1).

MPOC scores

The MPOC scores on most domains were fairly high on all assessments, mostly between five and six, meaning that services are delivered to a (fairly) great extent (Table 2). The domain ‘respectful and supportive care’ scored highest, and the domain ‘providing general information’ scored lowest on all assessments, with highest interquartile ranges, meaning wider dispersion.

The course of the MPOC scores over time

There were statistically significant changes over time regarding parents’ perceptions of services. Table 2 shows that the median scores decrease with increasing age on the scales enabling and partnership, providing specific information, co-ordinated and comprehensive care, and respectful and supportive care ($P < 0.001–0.008$, Friedman test). The median scale score was lower, but stable over time for the scale providing general information. Post-hoc analyses indicated that the parents of the children at time 3 (school) had significantly lower scores on all the decreasing scales compared with times 1 and 2 (preschool). No significant differences were found between times 1 and 2.

Differences in courses between parents of children attending different types of school

The differences in the course of MPOC scores between times 2 and 3 were explored for children attending a mainstream school (with or without special needs support) and children attending special education or day care program at time 3. No significant differences in the course of MPOC scores were found (Table 2).

Discussion

This study describes changes over time in the parents’ perception of family centredness of services before and after the transition from preschool to a school-based setting. The parents’ perception of family centredness of services decreased between preschool and school ages, indicating an association between change in the perception of FCS and the change of services and environment. This finding is also consistent with earlier results of cross-sectional studies (e.g. Dyke et al. 2006; Kertoy et al. 2013). The MPOC scores were highest in the domain ‘respectful and supportive care’ and lowest scores on ‘providing general information’, similar as in cross-sectional studies (S. M. King et al. 1996; Bjerre et al. 2004; van Schie et al. 2004; Dyke et al. 2006; Jeglinsky et al. 2012; Cunningham & Rosenbaum 2013; Kertoy et al. 2013). No differences were found in the course of perceived family centredness of services across different school settings. Differences in the courses could be expected because of differences in specialization or experience in dealing with children with CP between mainstream schools and specialized centres. Moreover, therapy sessions in special schools are integrated in the classroom, whilst in regular schools, therapy sessions typically are provided after school and thus at home or in the rehabilitation centre, resulting in more fragmented care. However, our data suggest no such difference in setting. Apparently, the transition from preschool to school itself changes the way parents experience the family centredness of services as measured by the MPOC-56.

The higher ratings on the MPOC during the preschool age are not unexpected.

The value of interventions for young children with disabilities is well acknowledged. This has resulted in

<table>
<thead>
<tr>
<th>Mean MPOC scores</th>
<th>Time 1; 2.5 years</th>
<th>Time 2; 3.5 years</th>
<th>Time 3; 4.5 years</th>
<th>Time*</th>
<th>School type**</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>Median (IQR)</td>
<td>Median (IQR)</td>
<td>Median (IQR)</td>
<td>$P$</td>
</tr>
<tr>
<td>Enabling and partnership</td>
<td>59</td>
<td>5.88 (1.25)</td>
<td>5.75 (1.06)</td>
<td>5.19 (1.36)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Providing general information</td>
<td>44</td>
<td>3.56 (2.39)</td>
<td>3.77 (1.95)</td>
<td>3.28 (1.98)</td>
<td>ns</td>
</tr>
<tr>
<td>Providing specific information</td>
<td>52</td>
<td>5.60 (1.66)</td>
<td>5.40 (1.75)</td>
<td>4.90 (1.75)</td>
<td>0.008</td>
</tr>
<tr>
<td>Co-ordinated and comprehensive care</td>
<td>57</td>
<td>5.82 (1.11)</td>
<td>5.75 (1.01)</td>
<td>5.19 (1.27)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Respectful and supportive care</td>
<td>59</td>
<td>5.89 (1.22)</td>
<td>5.89 (1.00)</td>
<td>5.56 (1.33)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

MPOC, Measure of Processes of Care; IQR, interquartile range.
* Differences in time, Friedman test.
** Differences in MPOC change score between times 2 and 3 between mainstream schools and special schools/day care, Mann–Whitney U tests.
funding and availability of much more intensive rehabilitation services for children before they are attending school, giving therapists a chance to develop a more intensive relation for collaboration with parents, which is an important feature of FCS (Dyke et al. 2006). Parents thus are naturally more involved in the intervention process, and therefore know the therapists better, and maybe also receive more information than parents with children who are attending school (Bjerre et al. 2004). In a school setting, therapies are typically integrated in the school program, so parents are likely less often present during therapy time, or are not present at all. This might result in less communication on therapy goals and progress.

In all rehabilitation settings, regular team conference meetings take place in which treatment goals are set and evaluated. Mostly, parents are involved in these meetings (Siebes et al. 2007b). However, the frequency of these meetings can differ between settings, and these meetings can differ in the way parents are actively involved. This could contribute to the wide distribution of MPOC scores in our study. Regular parental involvement in team conferences would help in shifting the focus from the child towards the family as a whole, and thus better experiences of family centredness of services.

Changing appreciations of different aspects of care when the type and amount of care stays the same is called response shift. Factors other than the care itself contribute to a different appreciation of the given care. These factors could be child-specific or family-specific. If parents become more familiar with the rehabilitation centre, they also become more critical about the rehabilitation services, and might provide lower MPOC scores (Siebes et al. 2007b). Knowing that certain services exist, yet are not provided, cause parents to be more critical about the services they receive; ‘ignorance is bliss’.

Summarized, objective change in rehabilitation services between settings, in combination with changes in subjective appreciations of care delivery (including response shift), may have contributed to a difference in the overall perception of family centredness of care before and after the transition from preschool to school.

The pattern of decline in the extent to which family-centred services are received by parents in the transition from preschool to school is similar across different school types. Apparently, the transition itself is an important factor in changing appreciation of FCS, and not so much the ‘setting’, the type of school the child attends.

Healthcare professionals working with children and their parents should therefore be aware of possible changes in the way services are experienced, especially in periods of transition when both the child and its environment change. These changes are not only accounted for by the care itself or the way care is delivered objectively (both qualitative as quantitative), but also and especially in the way it is perceived by parents. Awareness of these changes helps early signalling unmet needs and anticipation; forewarned is forearmed (Gorter’s ABC; Gorter 2012). Individual and repeated assessment of service needs could help in this process (Alsem et al. 2013). Improving parental guidance in the transition to primary school and the therapists involved in the new situation could help in improving FCS.

From the literature, we know that the parents of children with special needs do not feel informed adequately, especially about services for their child and for their family (Hummelinck & Pollock 2006; Cunningham & Rosenbaum 2013; Kertoy et al. 2013). This was also found in the present study in the parents of children with CP. Information provision is of importance for the parents for managing their child and to enable them in accessing services and benefits (Pain 1999). In order to improve information provision to parents, several instruments are being developed. In Canada, the KIT (Keeping it Together™) has been developed, an organizational tool to assist parents when interacting with different service systems (Stewart et al. 2006). In the Netherlands, recently, the Family Needs Inventory has been developed to inventory (e.g. informational, practical and emotional) the needs of parents of children with physical disabilities (Alsem et al. 2013).

These instruments might help healthcare providers in exploring the needs of parents in receiving the right information and support at the right time.

Limitations of this study

One of the limitations of this study is the number of dropouts and incomplete data, as well as a possible selection bias. Although there were no differences between the eligible group and the dropouts in different child characteristics, it is hard to say if and in which direction the sample may have been biased on the basis of other characteristics. The questionnaire may have attracted parents (1) who were more dissatisfied with rehabilitation care and wished to take the chance to express their dissatisfaction; (2) those who were more family-centred in thinking; or (3) those whose children were more heavily involved in therapy and thus had a greater investment in the rehabilitation care. Further longitudinal studies could provide insight in parental factors that are associated with this change.
A well-known problem in studies using the MPOC is handling items in which ‘not applicable’ is ticked. This results in a scale score being invalid, thereby losing possible valuable information. Ticking ‘not applicable’ by parents may either reflect ignorance with possible services or a service not being available. The distinction between not being available or not knowing that it is available does not show in the scale scores. Informing parents about all possible services is in line with FCS, and may enhance parental empowerment and involvement in care.

Although the parents are asked to fill in the MPOC to describe their experiences with all (healthcare) professionals that are involved with their child, most parents stated that they found it hard to give one rating for all professionals. It is possible that in a multidisciplinary team, one therapist could provide therapies more family centred than the other, or that therapies are delivered in different centres or day care centres. Giving a mean judgement over these services proved difficult for the parents. Possibly, therapists that are either very family centred or not family centred at all could dominate the overall judgement over ‘average’ therapists.

To date, the MPOC has been used mainly in cross-sectional studies, but the study described in this paper is one of the first to describe the course of perceived FCS over time in this age group. In the other longitudinal study by Siebes et al. (2007b) describing the stability of the MPOC over 1 year, it appeared that the MPOC scores decreased, although the appreciation of the care remained stable. This underlines the fact that with the current results, no conclusions can be drawn about the appreciation of care or the objective quality of paediatric rehabilitation services. However, we think that parental perception of services is an important factor in measuring the quality of care processes and should be taken into account in healthcare quality assessment.

Conclusion and future implications

The present study shows that the perception of family-centred services, reflected in MPOC scale scores, decreases after the transition from preschool programs to school-based services. Transitions in services for families with young children with cerebral palsy require awareness, preparation and collaboration between services to optimize outcomes. Providing general information is an area for improvement in paediatric rehabilitation services.

Key messages

- Parental perception of the family centredness of paediatric rehabilitation services declines after the transition from preschool programs to school-based services.
- Transitions in services for families with young children with cerebral palsy require awareness, preparation and collaboration between services to optimize outcomes.
- Providing general information is an area for improvement in paediatric rehabilitation services.

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Conflict of interest

The authors report no declaration of interest.

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