Team collaboration in Dutch paediatric rehabilitation. Cooperation between parents, rehabilitation professionals and special education professionals in the care for children with cerebral palsy

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A FAMILY-SPECIFIC USE OF THE MEASURE OF PROCESSES OF CARE FOR SERVICE PROVIDERS (MPOC-SP)

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Klaas Postema
Adri Vermeer
Abstract

Objective: To examine the validity and utility of the Dutch Measure of Processes of Care for Service Providers (MPOC-SP) as a family-specific measure.

Design: A validation study.

Setting: Five paediatric rehabilitation settings in the Netherlands.

Main measures: The MPOC-SP was utilized in a general (reflecting on services provided for all clients and clients’ families) and family-specific way (filled out in reference to a particular child and its family).

Subjects: Professionals providing rehabilitation and educational services to children with cerebral palsy.

Methods: For construct validity, Pearson’s product-moment correlation coefficients (r) between the scales were calculated. The ability of service providers to discriminate between general and family-specific ratings was examined by exploration of absolute difference scores.

Results: 116 service professionals filled out 240 family-specific MPOC-SPs. Additionally, a subgroup of 81 professionals filled out a general MPOC-SP. For each professional, family-specific and general scores were paired, resulting in 151 general–family-specific MPOC-SP pairs. The construct validity analyses confirmed the scale structure: 21 items (77.8%) loaded highest in the original MPOC-SP factors, and all items correlated best and significantly with their own scale score (r = .565 to .897; p < 0.001). Intercorrelations between the scales ranged from r = .159 to r = .522. In total, 94.4% of the mean absolute difference scores between general and family-specific scale scores were larger than the expected difference.

Conclusion: Service providers were able to discriminate between general and family-specific MPOC-SP item ratings. The family-specific MPOC-SP is a valid measure that can be used for individual evaluation of family-centred services and can be the impetus for family-related quality improvement.
5.1 Introduction

Today, the concept of family-centred service has become increasingly important in paediatric rehabilitation services. Family-centred service can be described as an holistic approach towards service delivery, in which the unique strengths, resources and set of needs of each child and its family form the base for a highly individualized and dynamic model of care (Dunst et al., 1988; King et al., 2004; MacKean et al., 2005). Parents and team members are equal partners and work together jointly, sharing aims, information, and responsibilities. Research indicates that providing family-centred service is associated with an increase in parents’ skills and knowledge about child development, improved parental satisfaction with services, decreased parental stress and improved well-being (King et al., 1996; King et al., 1998; Rosenbaum et al., 1998; King et al., 1999; Raina et al., 2005), improved children’s psychological adjustment (Stein & Jessop, 1984; Lewis et al., 1990; Stein & Jessop, 1991), and child developmental gains and skill acquisition (Moxley-Haegert & Serbin, 1983; Caro & Derevensky, 1991; Law et al., 1998).

Over the years, several measures have been developed to evaluate the family-centredness of services for children with disabilities from the perspective of parents and service providers. Of these measures, the Measure of Processes of Care for Service Providers (MPOC-SP) (Woodside et al., 2001) is the only broadly focused, valid, and reliable instrument that is available for the evaluation of family-centred service by service professionals (Dyke et al., 2006; Siebes et al., 2006). In an earlier study, the MPOC-SP was translated into Dutch and validated (Siebes et al., 2006). The authors reported on a good reliability and validity and service providers judged the practical applicability of the general MPOC-SP in daily practice positively. The MPOC-SP will be helpful to formulate topics for general quality improvement. However, the MPOC-SP is primarily developed to assess the quality of care for a group of parents only and does not take the uniqueness of each family into account, which is one of the pillars of family-centred service.

Truly family-centred service closely resembles the basic family-centred principles, acknowledging the uniqueness of each child and its family with an individual and dynamic approach. To accurately evaluate the degree of the family-centredness of care provided to a specific family and to improve this care, a measure of family-centred services that acknowledges the uniqueness of families, their preferences, and needs is requisite. Such a measure can be utilized for individual evaluation of family-centred services and quality control and to formulate topics for family-related quality improvement.

A target shift of the MPOC-SP towards individual families, instead of clients in general, can fulfil this need for a family-specific evaluation of family-centred service by service providers. When this measure is used in a family-specific way, each team member involved in the care for a particular family fills out one MPOC-SP for that family.

The use of the MPOC-SP as a family-specific measure is new, and therefore the main objective of the present study was to examine the validity and utility of the family-specific MPOC-SP. More specific, we examined (1) the construct validity of the family-specific MPOC-SP, and (2) the ability of service providers to discriminate between general ratings and family-specific ratings.

For simplicity, in this paper the term ‘general MPOC-SP’ will be used to designate the use of the measure that reflects the extent in which events and situations concern a service provider in general. The term ‘family-specific MPOC-SP’ will be used to indicate the measure that was filled out in reference to a particular child and its family.
5.2 Methods

5.2.1 Subjects and setting

In this study service providers of five rehabilitation centres and affiliated schools in the Netherlands who were involved in the care for children with cerebral palsy participated. These centres treated a different number of children and were situated in different parts of the Netherlands, covering both rural and urban areas. Although parents were not actually involved in the present study, their informed consent was obtained for the family-specific evaluation of their child’s care. Because of the descriptive nature of the present study, the medical ethics committee of the University of Groningen Medical Center decided that the study did not require their approval.

5.2.2 Instruments

The Measure of Processes of Care for Service Providers

The MPOC-SP was designed to systematically measure the family-centred behaviours of health professionals working with children with chronic health or developmental problems (Woodside et al., 2001; Siebes et al., 2006). The MPOC-SP is based on the 56-item Measure of Processes of Care (MPOC)(King et al., 1996) and has 27 items covering four scales. A complete list of items is provided in the Appendix 5.1. All response options are labelled, ranging from 1 (‘never’) to 7 (‘to a great extent’). The phrasing of items and response options captures both the quantitative and qualitative nature of service providers’ experiences, rather than a mere frequency count of occurrences.

In the general MPOC-SP, service providers are asked to think back over the past year and choose one of the seven response options to indicate ‘how much this event or situation happened to them’. By contrast, when the MPOC-SP is used family-specific, a service provider is asked to fill out the measure in reference to a particular child and its family. The contents of the general MPOC-SP and family-specific MPOC-SP are identical, only the target of the measure differs: the service provider’s treatment population in general, or a particular child and its family.

5.2.3 Procedure

The current study consisted of two phases: (1) collection of family-specific MPOC-SP data, and (2) collection of general MPOC-SP data. After parents’ informed consent was received, the involved service providers were mailed information about the study. Prior to the child’s first team conference after study entrance a family-specific MPOC-SP bearing the relevant child’s name was mailed to the involved service providers. Service providers could be involved in the treatment of more than one child, but did not receive more than one family-specific measure at the same time to improve independency of ratings. After completion of the family-specific MPOC-SP data collection (phase 1), all participating service providers simultaneously received a general MPOC-SP (phase 2). On average, the time between phase 1 and 2 was four months.
5.2.4 Analyses

To determine whether parametric statistics could be performed in the validation process, the skewness ($\mu_k$) and kurtosis ($\kappa$) of the items were examined at face value.

Construct validity family-specific MPOC-SP

The validation study’s sample size was based on general guidelines requiring five to ten subjects per variable or item in order to conduct the planned analyses (Nunnally & Wilson, 1975; Norman & Streiner, 1986), which means at least 135 questionnaires were needed for the validation of the family-specific MPOC-SP. For construct validity, the following research hypotheses were formulated: (1) Pearson’s product-moment correlation coefficients ($r$) between the scales of the family-specific MPOC-SP will be satisfactory, and (2) The family-specific MPOC-SP and the general MPOC-SP have a comparable multidimensional structure. First, Pearson’s product-moment correlation coefficient ($r$) was used to explore the measures’ factor structures by examining the correlation between an item score and its scale score without that item and other scale scores (Nunnally & Wilson, 1975). Second, a factor analysis with varimax rotation was performed to analyse the factor structure. In the construct validity study part, all family-specific questionnaires were included.

Service providers’ ability to discriminate between general and family-specific ratings

The ability of service providers to discriminate between general ratings and family-specific ratings was determined by exploration of absolute difference scores. For these analyses, only questionnaires were used of service providers who filled out a general MPOC-SP and at least one family-specific MPOC-SP. In the analyses the ratings of a service provider’s general MPOC-SP were paired with the ratings of each family-specific MPOC-SP of that service provider, resulting in general MPOC-SP–family-specific MPOC-SP pairs. Absolute difference scores were calculated by deducting service provider’s individual item scores of the general and each family-specific SP. For each scale, the mean absolute difference scores between family-specific and general ratings were compared with the difference scores between the first and second assessment (at three months) of the general MPOC-SP test-retest reliability study, in which the mean absolute scale difference scores ranged from 0.12 (Treating People Respectfully) to 0.25 (Providing General Information) (Siebes et al., 2006). In congruence with the family-centred principles, it was assumed that service providers were able to discriminate between general and family-specific ratings when the absolute difference scores between these ratings were larger than the expected differences which were based on the test-retest difference scores found in the general MPOC-SP validation study.

Finally, we examined whether service providers showed a specific bias, or in others words, we examined whether service providers scored higher (‘to a greater extent’) when filling out the general MPOC-SP or the family-specific MPOC-SP.
5.3 Results

5.3.1 Construct validity

Of the 293 family-specific MPOC-SP questionnaires that were sent out to 125 service providers of five rehabilitation centres and affiliated schools, 240 were returned and analyzed (mean response rate 81.9%). The family-specific MPOC-SPs were filled out for 44 children (29 boys and 15 girls, 4-8 years) and were filled out by 116 service providers (a mean of 2.1 questionnaires per service provider) representing 12 disciplines, among which physical therapists (n=22, 19.0%), teachers (n=21, 18.1%), speech therapists (n=18, 15.6%), occupational therapists (n=16, 13.8%), and rehabilitation specialists (n=11, 9.5%) were the largest respondent groups (76.0% of total group). Table 5.1 shows the numbers of participants and questionnaires that were included in the analyses to examine the family-bound MPOC-SP’s construct validity and service provider’s ability to discriminate between family-specific and general ratings, respectively.

Table 5.1 Number of service providers and questionnaires in the analyses

<table>
<thead>
<tr>
<th>Study part</th>
<th>n service providers</th>
<th>n family-specific MPOC-SP</th>
<th>n general MPOC-SP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Construct validity</td>
<td>116</td>
<td>240</td>
<td>0</td>
</tr>
<tr>
<td>Ability to discriminate between family-specific and general ratings</td>
<td>81(^1)</td>
<td>151(^2)</td>
<td>81</td>
</tr>
</tbody>
</table>

\(^1\) In the second part of the study only questionnaires were used of service providers who filled out a general MPOC-SP and at least one family-specific MPOC-SP.

\(^2\) The ratings of each family-specific MPOC-SP were matched to the ratings of that service provider’s general MPOC-SP.

Firstly, the distributions of the scores were examined to determine the skewness and kurtosis of the scale scores. Twenty-five items (93.0%) used the full range of the response options. Item 23 (‘promote family-to-family connections’) had the lowest mean item score (2.95, SD=1.68), whereas item 22 (‘treat children and their families as people rather than as “cases”’) had the highest mean score (5.83, SD=1.41). These items also scored lowest (3.70, SD=1.40) and highest (5.98, SD=1.14) in the general MPOC-SP validation study (Siebes et al., 2006). The item scores tended toward the higher end of the range, but the distributions were not found to be severely skewed (skew = -2.07 to .12). Furthermore, the analyses showed only two peaks in the item score distribution (kurtosis = 3.95 and 4.40 for item 17 and 22, respectively) (Stevens, 1986). Therefore, analysis of the ordinal data of the family-specific MPOC-SP with parametric statistics was allowed (Streiner & Norman, 1995; Thomas & Nelson, 2001).

Next, the correlations between the scales of the family-specific MPOC-SP were calculated using Pearson’s correlation coefficient (r). Providing General Information did not correlate significantly with Communicating Specific Information about the Child, all other scales intercorrelated significantly, if low to moderately (r = .176 to .522; see Table 5.2). Subsequently, the 27 MPOC-SP items were correlated with their own and the other three scale scores to examine the factor structure (using Pearson’s correlation coefficient). All items correlated best and significantly with their own scale score (p < 0.001) with r ranging from .565 to .897. Finally, a factor analysis with
varimax rotation was performed to examine the factor structure of the family-specific MPOC-SP. Seven factors with eigenvalues of at least 1.0 were identified, accounting for 72.2% of the variance. Our a priori interest in four factors, like the general MPOC-SP, was extracted by varimax rotation. This solution accounted for 58.3% of the variance. Twenty-one items (77.8%) loaded highest in the original general MPOC-SP factors.

Table 5.2 Correlation between the family-specific MPOC-SP scales using Pearson’s rank correlation coefficient (r)

<table>
<thead>
<tr>
<th>Scale name</th>
<th>PGI</th>
<th>CSI</th>
<th>TPR</th>
</tr>
</thead>
<tbody>
<tr>
<td>SIS</td>
<td>.315*</td>
<td>.491**</td>
<td>.522**</td>
</tr>
<tr>
<td>PGI</td>
<td>1</td>
<td>.159</td>
<td>.176*</td>
</tr>
<tr>
<td>CSI</td>
<td>1</td>
<td>.403**</td>
<td></td>
</tr>
</tbody>
</table>

SIS, Showing Interpersonal Sensitivity; PGI, Providing General Information; CSI, Communicating Specific Information about the Child; TPR, Treating People Respectfully. *Correlations with p<0.05 (2-tailed); **Correlations with p<0.01 (2-tailed). Range n 183 to 235.

5.3.2 Service provider’s ability to discriminate between general and family-specific ratings

The pairing of general and family-specific MPOC-SP ratings resulted in 151 general MPOC-SP–family-specific MPOC-SP pairs of 81 service providers. After that, absolute difference scores between a service provider’s general MPOC-SP scale score and a family-specific scale score were calculated to determine the ability of service providers to discriminate between general ratings and family-specific ratings. Figure 5.1 shows the mean absolute difference score values for all scales and pairs (n=122–151 pairs). In this Figure, the grey dashed lines represent the mean absolute difference scores for each scale, with m=1.24 (SD=0.77) for Showing Interpersonal Sensitivity, m=0.96 (SD=0.76) for Treating People Respectfully, m=1.33 (SD=1.01) for Communicating Specific Information about the Child, and m=1.36 (SD=0.80) for Providing General Information. The black lines represent the test-retest absolute difference scores of the MPOC-SP validation study at three months, with a range of 0.12 (Treating People Respectfully) to 0.25 (Providing General Information) (Siebes et al., 2006). The Figure illustrates that 1.3%, 4.0%, 8.2%, and 9.0% of the absolute difference scores were below the red lines for the scales Showing Interpersonal Sensitivity, Treating People Respectfully, Communicating Specific Information about the Child, and Providing General Information, respectively. Consequently, 94.4% of the difference scores were above the red lines, suggesting that service providers can make a distinction between family-specific and general ratings regarding their involvement in family-centred paediatric rehabilitation services.

Finally, we examined trends in the way service providers filled out the general and the family-specific MPOC-SP. These analyses showed that the mean family-specific MPOC-SP ratings (4.40; SD=0.86) were lower than the mean general MPOC-SP ratings (4.82; SD=0.66).
The aim of this study was to investigate the construct validity of the family-specific MPOC-SP and to determine whether service providers can discriminate between general ratings and family-specific ratings. The Pearson correlations between the family-specific MPOC-SP scales were not all significant, but since the overall results fulfil our hypotheses, we consider the construct validity as satisfactory. Additional analyses confirmed that service providers can make a distinction between general MPOC-SP ratings and family-specific MPOC-SP ratings.

**Figure 5.1.** Absolute difference between a service provider’s general MPOC-SP scale score and a family-specific scale score (n=122–151 pairs) reflecting the ability of service providers to discriminate between general ratings and family-specific ratings. The grey dashed lines represent the mean absolute difference scores for each scale, with m=1.24 (SD=0.77) for Showing Interpersonal Sensitivity (SIS), m=1.36 (SD=0.80) for Providing General Information (PGI), m=1.33 (SD=1.01) for Communicating Specific Information about the Child (CSI), and m=0.96 (SD=0.76) for Treating People Respectfully (TPR). The black lines represent the test-retest absolute difference scores of the MPOC-SP validation study at three months, with values of 0.20 (SIS), 0.25 (PGI), 0.24 (CSI), and 0.12 (TPR).

### 5.4 Discussion

The aim of this study was to investigate the construct validity of the family-specific MPOC-SP and to determine whether service providers can discriminate between general ratings and family-specific ratings. The Pearson correlations between the family-specific MPOC-SP scales were not all significant, but since the overall results fulfil our hypotheses, we consider the construct validity as satisfactory. Additional analyses confirmed that service providers can make a distinction between general MPOC-SP ratings and family-specific MPOC-SP ratings.
Truly family-centred service should be individually tailored, and therefore asks for a family-specific evaluation. The family-specific MPOC-SP is the best choice to evaluate such individualized care attuned to a family’s specific wishes, needs and preferences. When filled out in a family-specific way, the MPOC-SP can be utilized for individual evaluation of family-centred services and quality control and to formulate topics for family-related quality improvement, whereas the general MPOC-SP provides a broader view. Founded on the present and earlier studies (Siebes et al., 2006; Siebes et al., 2007), Table 5.3 offers guidelines on the general and family-specific use of the measure.

Nevertheless, some critical remarks have to be made. Although the majority of the participating service providers worked together in a team and filled out more than one family-specific MPOC-SP, independence of cases was assumed in our analyses. However, even though the questionnaires were each filled out at a different point in time and for an individual child and its family, hereby minimizing a possible bias, the bias within a service provider can only be controlled for by means of a multi level analysis with a large number of cases.

As is the case with all other self-evaluative measurement tools, it remains unclear whether the respondents mirror on actual or on desired behaviours, and whether their scores are inflated or deflated to some extent. Therefore, the scores may not accurately reflect actual behaviours of service providers. An extended observational study on actual family-centred behaviours of service providers can provide insight in eventual differences between actual and desired behaviours.

The current study could have been constrained by the specific study target group, that is, children diagnosed with cerebral palsy. However, in family-centred service the way in which families are involved in treatment is not predetermined by the child’s diagnosis, but each family is regarded as a unique system that is in need for a unique approach. Therefore, in a family-centred treatment setting our limited diagnose group should not negatively influence the generalizability of our findings.

**Table 5.3.** Guidelines on the use of the general MPOC-SP and the family-specific MPOC-SP

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>General MPOC-SP</th>
<th>Family-specific MPOC-SP</th>
</tr>
</thead>
<tbody>
<tr>
<td>International comparability of results¹</td>
<td>+</td>
<td>–</td>
</tr>
<tr>
<td>Respondent burden²</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Use for general evaluation of family-centred service and quality control</td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Use for individual evaluation of family-centred service and quality control</td>
<td>–</td>
<td>++</td>
</tr>
<tr>
<td>Use to formulate topics for general quality improvement</td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Use to formulate topics for family-related quality improvement</td>
<td>–</td>
<td>++</td>
</tr>
</tbody>
</table>

¹– = low comparability; + = good comparability. ²+ = low burden, 5 to 10 minutes. When the family-specific MPOC-SP is used, the burden raises when the individual questionnaires have to be filled out all at once. We advise to choose fixed moments to fill out the family-specific MPOC-SP, for instance, prior to the yearly team conference meeting. ³+ = intermediate utility; ++ = good utility.
The analyses showed that service providers gave higher ratings on the general MPOC-SP than on the family-specific MPOC-SP. This could imply that service providers tend to score lower when they think of one particular family when they fill out the MPOC-SP family-specific, but it could also suggest that service providers work less family-centred when they work with children with cerebral palsy, or even the designated age group of the target population could have suppressed the family-specific ratings.

Our study characteristics are formed by the complex care process of children with multiple disabilities and the numerous professions involved, resulting in highly intercorrelated data. This limited our analyses; additional research with a broader scope in a larger sample is required to clarify the aforementioned assumptions. Such a study can provide quantitative statistics on differences between general and family-specific ratings, whereas the present study was restricted to a descriptive nature.

In the present study sample, large teams were involved in the care process of participating families. Therefore, a considerable amount of data is needed to study possible roles of different professions in the process of care and to show differences between families. Moreover, in a larger study sample intra-individual differences can be specified, which was not possible in the present study due to the low numbers of service providers who filled out two or more family-specific questionnaires. Nevertheless, we consider the results of this study as a rationale and a catalyst for the family-specific use of the MPOC-SP. Once a family-specific use of the measure is ‘in the system’ and service providers are keen to explore further uses of the measure we can follow up on our research.

The current study confirmed that service providers are able to discriminate between general and family-specific MPOC-SP ratings. With these findings, a truly family-specific evaluation of services is facilitated, in which MPOC scores provided by parents can be compared with family-specific MPOC-SP scores of team members who are involved in the child’s care process. Comparisons between the ratings of parents and service providers are useful because different roles enable people to see different parts of the overall service. The evaluation of family-centred service should be a service wide process, involving the perceptions of people in various positions, including at least parents and service providers (Dyke et al., 2006). In a study by Nijhuis et al. (2007) such a comparison showed that service receivers and service providers differed considerably in what they deemed essential in family-centred care, and that opinions on what constitutes proper service delivery needs to be explored and attuned.

As far as we know, at this time the MPOC-SP is applied as a family-specific measure in the Netherlands only. We consider the family-specific MPOC-SP to be the most suitable instrument for individual evaluation of family-centred services. Family-specific MPOC-SP results can initiate family-related quality improvement.

### 5.5 Clinical Messages

- The construct validity of the family-specific MPOC-SP is satisfactory.
- Service providers can discriminate between general MPOC-SP ratings and family-specific MPOC-SP ratings.
- The family-specific MPOC-SP can be used for the individual evaluation of family-centred services and can be the impetus for family-related quality improvement.
5.6 ACKNOWLEDGEMENTS

We gratefully acknowledge Peter Rosenbaum, Susanne King, and their colleagues of the CanChild Centre for Childhood Disability Research for sharing their knowledge and making the MPOC-SP available. Thanks are also due to the health-care professionals who took part in this study, and the support staff of all participating centres: Centrum voor Revalidatie-Beatrixoord, Revalidatie Friesland, Het Roessingh-Centrum voor Revalidatie, Revalidatiecentrum Blixembosch, Sophia Revalidatie, Mytylschool Pr. Johan Friso, Onderwijscentrum Het Roessingh, Mytylschool Eindhoven, School Lyndensteyn, and Mytylschool De Piramide. We are indebted to Grieke Olijve for her help with the data collection in this study, and Jan Willem Gorter and Petra van Schie for commenting on earlier drafts of this paper.

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5.7 REFERENCES


# Appendix 5.1 Items and Scaling of MPOC-SP

Table A5.1. Items and scaling of the Measure of Processes of Care for Service Providers (MPOC-SP)

<table>
<thead>
<tr>
<th>Item no.</th>
<th>Item description*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Showing Interpersonal Sensitivity</strong></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Suggest treatment/management activities that fit with each family's needs and lifestyle?</td>
</tr>
<tr>
<td>2</td>
<td>Offer parents and children positive feedback or encouragement?</td>
</tr>
<tr>
<td>3</td>
<td>Take the time to establish rapport with parents and children?</td>
</tr>
<tr>
<td>4</td>
<td>Discuss expectations for each child with other service providers, to ensure consistency of thought and action?</td>
</tr>
<tr>
<td>5</td>
<td>Tell parents about options for services or treatments for their child?</td>
</tr>
<tr>
<td>8</td>
<td>Discuss/explore each family's feelings about having a child with special needs?</td>
</tr>
<tr>
<td>9</td>
<td>Anticipate parents' concerns by offering information even before they ask?</td>
</tr>
<tr>
<td>11</td>
<td>Let parents choose when to receive information and the type of information they wanted?</td>
</tr>
<tr>
<td>12</td>
<td>Help each family to secure a stable relationship with at least one service provider who works with the child and parents over a long period of time?</td>
</tr>
<tr>
<td>21</td>
<td>Help parents to feel competent in their roles as parents?</td>
</tr>
<tr>
<td><strong>Treating People Respectfully</strong></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Accept parents and their family in a non-judgemental way?</td>
</tr>
<tr>
<td>7</td>
<td>Trust parents as the 'experts' on their child?</td>
</tr>
<tr>
<td>10</td>
<td>Make sure parents had a chance to say what was important to them?</td>
</tr>
<tr>
<td>13</td>
<td>Answer parents' questions completely?</td>
</tr>
<tr>
<td>17</td>
<td>Treat each parent as an individual rather than as a 'typical' parent of a child with a 'problem'?</td>
</tr>
<tr>
<td>18</td>
<td>Treat parents as equals rather than just as the parent of a patient?</td>
</tr>
<tr>
<td>19</td>
<td>Make sure parents had opportunities to explain their treatment goals and needs?</td>
</tr>
<tr>
<td>20</td>
<td>Help parents feel like a partner in their child's care?</td>
</tr>
<tr>
<td>22</td>
<td>Treat children and their families as people rather than as a 'cases'?</td>
</tr>
<tr>
<td><strong>Communicating Specific Information about the Child</strong></td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>Tell parents about the results from tests and/or assessments?</td>
</tr>
<tr>
<td>15</td>
<td>Provide parents with written information about their child's condition, progress, or treatment?</td>
</tr>
<tr>
<td>16</td>
<td>Tell parents details about their child's services, such as the types, reasons for, and durations of treatment/management?</td>
</tr>
<tr>
<td><strong>Providing General Information</strong></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>Promote family-to-family 'connections' for social, informational or shared experiences?</td>
</tr>
<tr>
<td>24</td>
<td>Provide support to help families cope with the impact of their child's chronic condition?</td>
</tr>
<tr>
<td>25</td>
<td>Provide advice on how to get information or to contact other parents?</td>
</tr>
<tr>
<td>26</td>
<td>Provide opportunities for the entire family, including siblings, to obtain information?</td>
</tr>
<tr>
<td>27</td>
<td>Have general information available about different concerns?</td>
</tr>
</tbody>
</table>

*Each item begins, 'In the past year, to what extent did you...'; or, where applicable, 'In the past year, to what extent did you (or your organization)...'.

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