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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GOAL SETTING IN DUTCH PAEDIATRIC REHABILITATION

ARE THE NEEDS AND PRINCIPAL PROBLEMS OF CHILDREN WITH CEREBRAL PALSY INTEGRATED INTO THEIR REHABILITATION GOALS?
ABSTRACT

Objective: To evaluate whether the needs and principal problems of children with cerebral palsy (CP) as formulated in their interdisciplinary rehabilitation reports are integrated into the goal descriptions and whether this depends on the nature of the needs and problems.

Design: Descriptive multiple-case study

Setting: Five Dutch paediatric rehabilitation facilities

Subjects: The rehabilitation profiles of 41 children with CP aged between 4 and 8 years

Methods: The raw text data were extracted and organised, after which two raters independently linked the extracted content to the categories of the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY). Matches between needs, problems and goals were identified by ICF-CY-code comparisons.

Results: The Cohen’s Kappa’s for ICF-CY encoding were all in the range of “fair to good” (0.52-0.78). For five children (12%) no needs had been formulated and the reports of ten (24%) were excluded from further analyses as they lacked a principal goal. In the 31 reports analysed, 29 (23%) need constructs and 46 (46%) problem constructs were incorporated into the goals. Of the total of 95 goal constructs 49 (52%) were not related to either a need or a problem construct. No clear relationship could be established between the type of needs and problems and their inclusion or exclusion in the principal goals.

Conclusion: Overall, the integration of the needs and principal problems of children in their rehabilitation goals was not optimal. However, integration was difficult to objectify because needs, problems and goals were poorly documented.
7.1 Introduction

Most children seen in paediatric rehabilitation have a chronic condition that requires continued and tailored attention and treatment in the different developmental stages of their lives. Rehabilitation therapy, personalised education at mainstream or specialised schools and parental care in the home are all three important parts of the rehabilitation process. Since developments in these areas are all intertwined, the main concerns, needs, priorities and goals require careful deliberation involving all three parties concerned.

In paediatric rehabilitation a range of (varying) professionals from different organizations work together in specialised teams to meet the often complex needs of the child and its parents. It is widely recognised that close collaboration between these professionals (Bakheit, 1996; Barnes & Turner, 2001; Hinojosa et al., 2001; Robards, 1994; Rosen et al., 1998; Thylefors et al., 2000; Yerbuary, 1997) and the child’s parents (DePompei & Williams, 1994; Hostler, 1999; King et al., 1997; King et al., 2004; Nijhuis et al., 2007; Rosenbaum et al., 1998) is crucial to the quality of the health care provided. Accordingly, shared interdisciplinary goals, in which the different perspectives of all parties involved are integrated, are of major importance (Bakheit, 1996; De Moor et al., 1999; DePompei & Williams, 1994; Dule et al., 1999; Fell & Pierce, 1995; Roelofsen et al., 2001), where goal setting requires careful negotiation between parents and professionals to identify the desired outcome and direct the rehabilitation process (Holliday et al., 2005; Playford et al., 2000; Randall & McEwen, 2000; Schut & Stam, 1994; Siegert & Taylor, 2004).

Yet, even though it has been widely recognised as a key element, a recent efficacy review concluded that convincing evidence as to the most effective approach to goal setting in rehabilitation is still lacking (Levack et al., 2006). In our literature review of the salient elements of team collaboration, we also came to the conclusion that, despite extensive descriptions of the need for joint goal setting, none of the studies we reviewed described how effective different goal-setting procedures were (Nijhuis et al., 2007). After several years describing the theoretical foundations and desired improvements in current goal-setting strategies, we wanted to investigate goal-setting processes empirically in clinical practice.

The rehabilitation activities profile for Children (the Children’s RAP)

In paediatric rehabilitation an interdisciplinary team approach is preferred, characterised by centralised client needs, shared problem formulation and shared formulation of treatment goals, which are reviewed in regularly scheduled team meetings (Bakheit, 1996; De Moor et al., 1999; Robards, 1994; Roelofsen et al., 2002; Thylefors et al., 2000). To this end, in 2001 the Rehabilitation Activities Profile for children (the Children’s RAP) was developed and implemented in all regional paediatric rehabilitation settings in the Netherlands (Roelofsen et al., 2001). The profile or treatment plan provides professionals and parents with a common language about the child’s and parental abilities and a common reference framework for their respective needs, helping all parties to better verbalize the child’s and parents’ actual problems during the (annual and semi-annual) team conferences. Furthermore, the instrument helps the team formulate the interdisciplinary rehabilitation goals adjusted to the needs of the child and its proxies1, and the evaluation of these goals.

1 “proxies” refers to the child’s parents, siblings, peers and all significant others in the child’s environment.
In this goal-setting process the perspective of child and proxies is represented in their respective needs that have been jointly formulated. A need has been defined in the Children’s RAP manual as a concept describing a problem that hinders the child or parents in daily life or describing the wishes or expectations the child, parents or environment have regarding treatment or education.

Although the children’s RAP prescribes to report the needs of child and proxies, in an earlier study into how the needs of children with cerebral palsy (CP) are documented in the Children’s RAP (Nijhuis et al., submitted), we found that 91% of the needs concerned the child and only 4% the parents and 2% the environmental system. For the remaining 3% it was not possible to identify whom the need pertained to. In the current study we will therefore solely consider the child’s need, which will mostly be formulated by the child’s parents (or proxies).

The perspective of the professional team members, i.e. the rehabilitation and educational professionals, is represented in the definition of the principal problem. A principal problem has been defined in the Children’s RAP manual as a concept that describes the at present most important problem that hinders the child or parents in daily life or describes the aspect that hinders or stagnates the child’s development at present or in the future. In this way the principal problem is the by the team considered most important problem at this moment. After the needs and problems have been established, the profile recommends that the parents and professionals should jointly discuss and formulate the principal goal. The principal goal is defined as the effect, or result the team and the parents together aim at. The principal goal is directional for the discipline-specific treatment and education goals and is phrased in terms of children’s and parental activities. Optimally, the two perspectives (needs and problems) are thus incorporated into a shared principal goal.

With the present study we investigated whether the parental and professional perspectives are indeed integrated into the goals as documented in the RAPs of children with CP currently receiving rehabilitation, focusing on the coherence between the child’s needs, principal problem and principal goal. Five research questions were addressed:
1. Are the child’s formulated needs integrated into the principal rehabilitation goals?
2. Are the child’s formulated principal problems integrated into the principal goals?
3. How many goals are formulated and which of those are directly related to either the needs or problems of the child concerned?
4. What is the content of the goals that are not related to the child’s needs and principal problems?
5. Does integration of needs and problems depend on their content?

7.2 METHODS

7.2.1 Material

Parents were asked to give their consent for the use of their child’s rehabilitation profile (Children’s RAP) if their child was diagnosed with cerebral palsy (CP), was aged between 4 and 8 years and attended a school for special education that was affiliated with one of the participating rehabilitation centres. Because of the descriptive nature of the study, the medical ethics committee of the University of Groningen Medical Center decided that no ethical approval by the committee was needed. Following parental consent, we evaluated the RAPs of 41 children (28 boys, 13 girls;
mean age 6.8y, SD 1.3y) as completed by five rehabilitation centres and affiliated local schools for special education from regions across the country. The children’s intensity of disability varied. The Gross Motor Function Classification Measure (GMFCS) (Palisano et al., 1997) was used to assess intensity of disability. The GMFCS classifications of the participating children ranged from level I (“the child is able to walk and run, but has some difficulty with more advanced skills”) to level V (“the child has very limited voluntary movement ability”). Twenty of the children were classified as level I, two as level II, six as level III, nine as level IV, and four as level V. The centres represented approximately a quarter of our national, registered paediatric rehabilitation centres and were all familiar with using the Children’s RAP (Roelofsen et al., 2001).

The professionals (86% women (N=146); mean age 39 yrs, SD 10 yrs) contributing to the treatment of one or more of the children represented 11 disciplines; 81 professionals were associated with the rehabilitation centres and 89 professionals with the affiliated schools. For 45% (N=76) work experience exceeded 8 years, for 22% (N=37) it ranged between 3 to 8 years and in 34% (N=57) it comprised fewer than 3 years.

7.2.2 Procedure

The needs, principal problems and shared principal goals for each child were derived from a copy of the child’s RAP drafted during the most recent team conference. Data collection and analysis comprised the following four steps:

**Step 1.** The first author (BJGN) screened the original text of each child’s report and extracted the details (verbatim notes) entered under the following Children’s RAP headings, child or parental needs, principal problems and principal goals.

**Step 2.** Subsequently, per Children’s RAP theme (needs, problems or goals) the raw data were organised in elements describing a single issue. Each new issue was given a new line resulting in a final document listing all single entries per child and per theme, which will henceforth be referred to as “concepts”.

**Step 3.** For the content analysis two encoders (BJGN and HAR) independently linked all concepts to the components, domains and categories (three-digit codes) of the International Classification of Functioning, Disability, and Health for Children and Youth (ICF-CY) (World Health Organization, 2007) (see relevant section below) in accordance with the manual of the International Classification of Functioning, Disability, and Health (ICF) (World Health Organization, 2001) and the Cieza et al. (2005) rules for linking health-status measures to the ICF. Consensus was established and ICF-CY encoding was practised during a pilot session using three randomly selected profiles. Although the ICF-CY has a nondefinable category to classify concepts that do not allow classification into a specific ICF-CY category, it was decided to extend the linking parameters with three nondefinable categories to allow more specific classification of concepts describing an overall aspect of the child’s motor function, development or balance control that could not be assigned to any of the existing ICF-CY categories. Having analysed all profiles, the raters discussed differences until consensus was reached.

As the ICF criteria demand as precise a linking as possible, a particular concept may fit more than one ICF-CY code. Although classified as a single concept, the goal “Tim is able to cycle in busy traffic”, for example, should be linked to both code d475 (cycling) and to code e2 (busy traffic).
Each concept can be linked to one or more ICF-CY codes, which may result in a potential difference between the number of concepts and ICF-CY codes per child. To emphasise the difference between the concepts and the ICF-CY codes, we will in the remainder of this paper refer to the latter as (ICF-CY) “constructs”.

The interrater reliability of the raters’ scores in step 3 was calculated prior to the final consensus discussion by means of Cohen’s Kappa (see Analysis section).

**Step 4.** Finally, we determined if the child’s needs and principal problems were integrated into the profile’s principal goal(s). We considered one or both integrated if the ICF-CY codes of the *need* or *problem constructs* fell within the same ICF-CY category as the ICF-CY codes of the *principal-goal constructs*. When they did, this was noted as a “match”. Subsequently, in order to determine the proportion of goals that were related to a need or problem construct, the matches between goal constructs and need and problem constructs, respectively, was determined in the same way.

The described 4-step analysis accordingly resulted in 41 lists specifying each child’s needs, principal problems and principal goals linked to ICF-CY-codes (referred to as need constructs, problem constructs and goal constructs), detailing for each need and problem construct whether it was incorporated into the goal construct(s) and for each goal construct whether it was related to a need or problem construct.

**The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)**

We used the ICF for children and youths (ICF-CY) (World Health Organization, 2007) to classify the Children’s RAP concepts because the original ICF did not adequately capture the functional characteristics specific to the developing child (World Health Organization, 2001).

The ICF-CY has two-parts (Health condition and Contextual factors), each consisting of two separate components; (1) body functions (b) and Structure (s), and Activities and participation (d) and (2) Environmental (e) and personal factors. The ICF-CY provides a list of numerous codes representing detailed categories to describe respectively the individual’s integrity of body functions and structures, the ability to perform daily-life activities and the scope of the individual’s participation, and environmental factors that might facilitate or impede functioning and personal factors. For the complete list of ICF-CY domains and categories see the first column of table 7.2 (see result section).

Like the ICF, the ICF-CY is a structured instrument: its codes consist of a letter (b, s, d or e) followed by one or more numbers, where the letter refers to the domain and the subsequent numbers to the level of specification (chapter, paragraph, subparagraph etc.) of the domain.

**7.2.3 Analysis**

The data were analysed using the Statistical Package for the Social Sciences (SPSS-14). Cohen’s Kappa was calculated as a measure of interrater reliability for the ICF-CY-linking procedure. Cohen’s Kappa values were categorised as “poor” when lower then 0.41, “fair to good” when between 0.41 and 0.8, and “almost perfect” when exceeding 0.8 (Landis & Koch, 1977).

The identification of matches between needs, problems and goals was performed at the ICF-CY
category level (single digit codes, i.e. b1, d2, e4) and for each child separately. Because the total number of needs, problems and goals differs per child and per child duplicate ICF-CY construct codes can be identified in the three different Children's RAP themes, the number of need-goal matches can differ from the number of goal-need matches, as can the number of problem-goal matches from the number of goal-problem matches. To provide a comprehensive analysis of the relationship between the three Children's RAP themes, matches in ICF-CY codes were identified in the following combinations of ICF-CY constructs: needs-goals, problems-goals, goals-needs and goals-problems. Constructs that were coded as “not definable (nd)” in the ICF-CY (i.e. could not be linked to a specific ICF-CY code) were handled as non-matches in the analysis. The added nd codes (nd motor, nd development and nd balance) were handled as matches if a combination of one of these categories was found (analogous to all other ICF-CY-category matches). We used descriptive frequency analysis to evaluate the matches between needs, problems and goals and to describe whether matches were equally distributed over the ICF-CY domains and categories (research questions 4 and 5).

7.3 Results

The 4-step analysis and data categorisation resulted in a different number of concepts (step 2) and ICF-CY constructs (step 3) per category. Table 7.1 itemises the number of concepts and ICF-CY constructs per category and the ICF-CY-linking interrater reliability scores. At both the ICF-CY domain and category level the Cohen's Kappa values were in the range of “fair to good” with the lowest values for the linking of ICF-CY codes to the principal goal constructs.

For 10 of the 41 children (24%) no principal goals were formulated in the Children's RAP, which reports were excluded from further analyses (see Table 7.1 for the final number of ICF-CY constructs as used in the further analyses).

Table 7.1 Number of extracted Children's RAP* concepts and corresponding ICF-CY** constructs for the three Children's RAP themes and the interrater reliability scores (Cohen's Kappas) for the ICF-CY classification per profile

<table>
<thead>
<tr>
<th>Theme</th>
<th>Children's RAP concepts (Step 2)</th>
<th>Interrater reliability</th>
<th>ICF-CY constructs (Step 3)</th>
<th>ICF-CY constructs*** (Final analysis)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=41 children</td>
<td>Domains</td>
<td>Categories</td>
<td>N=41 children</td>
</tr>
<tr>
<td>Needs of child and proxies</td>
<td>163</td>
<td>0.78</td>
<td>0.78</td>
<td>182</td>
</tr>
<tr>
<td>Principal problems</td>
<td>121</td>
<td>0.61</td>
<td>0.63</td>
<td>147</td>
</tr>
<tr>
<td>Principal goals</td>
<td>71</td>
<td>0.69</td>
<td>0.52</td>
<td>95</td>
</tr>
</tbody>
</table>

* Children's RAP= Rehabilitation Activities Profile for Children
** ICF-CY = International Classification of Functioning, Disability and Health for Children and Youth
*** The profiles of 10 children were excluded from the final analysis because of missing data
7.3.1 Integration of needs

The child-specific need-integration analysis revealed that 29 (23%) of the 125 need constructs identified, matched one or more goal constructs. The number of need constructs varied widely per child (0-16 needs per child; mean 4.8, SD 3.4). On average 1.1 (1.0, range 0-3) need constructs per child matched one of its goal constructs.

The left-hand panel of Figure 7.1 depicts the content matches between needs and goals for each child. In this figure each horizontal bar represents the number of need constructs per child, with black colour shading for matches and grey shading for the non-matches. It shows that for five of the 31 children (16%, child: 11, 16, 24, 29, 30) no needs were formulated in the reports. The panel also illustrates that for eight of the 26 children for whom needs were formulated (31%; child: 8, 9, 10, 12, 17, 19, 26, 28) none of the needs matched their goal constructs (total grey bars). For three children (12%; child: 3, 27 and 31) the full content of their needs matched their principal goals (black bars).
7.3.2 Integration of principal problems

In the problem-integration analysis, 100 problem constructs were identified with the number again varying considerably per child (range 1-13; mean 3.2, SD 2.5). Of these constructs on average 1.4 (1.5, range 0-6) matched a goal construct.

The right-hand panel of Figure 7.1 shows the matches and non-matches for the principal-problem and goal constructs per child. Of the 100 problem constructs 46 (46%) codes corresponded to a goal construct. For eight children (26%; child: 3, 8, 9, 10, 12, 17, 19, 30) no match was found. For seven children (23%; child: 6, 14, 15, 16, 24, 26, 27) the content of all problem concepts matched their goal construct(s).

Together, the two panels demonstrate that fewer problems than needs were formulated for this group of children. Nevertheless, 46% of the identified problems matched a goal construct whereas of the formulated needs only 23% did. Furthermore, for six children (19%, child: 8, 9, 10, 12, 17 and 19) no matches were found for either need or problem constructs, which means that the goals for these children did not take any of these variables into account. For one child (30) no needs had been identified and none of the problem constructs were integrated into its treatment goals.
7.3.3 Related principal goals

As stated before, for 10 of the 41 children (24%) no principal goals were formulated in the Children’s RAP, which reports unfortunately had to be excluded from further analyses. In the remaining rehabilitation reports of 31 participating children, 95 goal constructs were identified. Also the number of goal constructs varied widely per child (1-10 goals per child; mean 3.1, SD 2.0). On average 1.0 (range 0-3) goal-construct was related to a need and 1.3 (SD 1.1, range 0-5) to a problem construct.

The last row of Table 7.2 lists the number of matches of goal constructs with either need or problem constructs and with both, as well as the non-matches. Forty-six (48%) of the 95 goals were related: 7 (7%) to a need, 14 (15%) to a problem and 25 (26%) to both a need and a problem construct. Thus, 49 goal constructs (52%) were unrelated to either variable. Figure 7.2 depicts the matches and non-matches per child. The same as in figure 7.1, each bar represents a child and the length of the bar indicates the number of goal constructs identified for this child. The different shadings indicate whether the goal construct was related to a need, to a problem, to both a need and a problem or not related (see legend for shadings). For 6 children (19%; child: 4, 5, 7, 14, 23, 27) the goals all related to both their needs and their problems, for one child (3%; child: 3) they related to its needs only and for 7 children (23%; child: 8, 9, 10, 12, 17, 19, 30) the goals were related to neither the need or problem constructs of that child.

7.3.4 Content analysis of unrelated goals

Figure 7.3 shows the distribution of matching and non-matching goal constructs for the different ICF-CY categories. In this figure the bars represent the number of goal constructs in the different ICF-CY categories and the shading of the bars indicates whether the goals matched or did not match with a need or problem construct(s). As figure 7.3 shows, and table 7.2 in more detail, there were 49 non-matches and the categories of the environmental factors domain (e1, e2, e3 and e5, n=13) and the three non-definable categories (motor, development, and balance, n= 4) contained mostly unrelated goal-constructs. Also the ICF-CY constructs in activities and participation (d, n=2), self-care (d5, n=2) and major life areas (d8, n=3) often did not match with the need and problem constructs of the children.

Table 7.2. In the first column, in percentages the distribution of matches and non-matches between need and principal problem constructs and the goal constructs across the ICF-CY categories, between parenthesis total N in that category (N=31 children). In the last column, number of matches and mismatches of goal constructs with need and problem constructs per ICF-CY category (N=31 children).
<table>
<thead>
<tr>
<th>ICF Domain and Category</th>
<th>Percentages of needs and problems that matched with a goal-construct</th>
<th>Amount of matches with need- and problem- constructs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Needs- goals (total N)</td>
<td>Problems-goals goals (total N)</td>
</tr>
<tr>
<td><strong>Body functions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b) Body functions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>not specified</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b1) Mental functions</td>
<td>46% (13)</td>
<td>46% (35)</td>
</tr>
<tr>
<td>(b2) Sensory functions</td>
<td>50% (2)</td>
<td></td>
</tr>
<tr>
<td>and pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b3) Voice and Speech</td>
<td>100% (1)</td>
<td>66% (3)</td>
</tr>
<tr>
<td>Functions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b4) Functions of the</td>
<td>100% (1)</td>
<td>50% (2)</td>
</tr>
<tr>
<td>cardiovascular,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>haematological,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>immunological and</td>
<td></td>
<td></td>
</tr>
<tr>
<td>respiratory systems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b5) Functions of the</td>
<td>0% (1)</td>
<td></td>
</tr>
<tr>
<td>digestive, metabolic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>and endocrine systems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b6) Genitourinary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>and reproductive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>functions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b7) Neuromusculo-skel-</td>
<td>20% (5)</td>
<td>75% (4)</td>
</tr>
<tr>
<td>etic and</td>
<td></td>
<td></td>
</tr>
<tr>
<td>movement related</td>
<td></td>
<td></td>
</tr>
<tr>
<td>functions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b8) Functions of the</td>
<td></td>
<td></td>
</tr>
<tr>
<td>skin and related</td>
<td></td>
<td></td>
</tr>
<tr>
<td>systems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>**Activities and</td>
<td></td>
<td></td>
</tr>
<tr>
<td>participation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>not specified</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(d1) Learning and</td>
<td>50% (14)</td>
<td>71% (7)</td>
</tr>
<tr>
<td>applying knowledge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(d2) General tasks</td>
<td>33% (12)</td>
<td>54% (13)</td>
</tr>
<tr>
<td>and demands</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(d3) Communication</td>
<td>0% (4)</td>
<td>0% (3)</td>
</tr>
<tr>
<td>(d4) Mobility</td>
<td>10% (29)</td>
<td>75% (4)</td>
</tr>
<tr>
<td>(d5) Self-care</td>
<td>0 (7)</td>
<td></td>
</tr>
<tr>
<td>(d6) Domestic life</td>
<td>0 (1)</td>
<td>0 (2)</td>
</tr>
<tr>
<td>(d7) Interpersonal</td>
<td>40% (5)</td>
<td>75% (4)</td>
</tr>
<tr>
<td>interactions and</td>
<td></td>
<td></td>
</tr>
<tr>
<td>relationships</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(d8) Major life areas</td>
<td>100% (2)</td>
<td>100% (2)</td>
</tr>
<tr>
<td>(d9) Community, social</td>
<td>0 (4)</td>
<td>100% (1)</td>
</tr>
<tr>
<td>and civic life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>**Environmental factors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>not specified</td>
<td>0% (1)</td>
<td>0% (1)</td>
</tr>
<tr>
<td>(e1) Products and</td>
<td>0% (7)</td>
<td></td>
</tr>
<tr>
<td>technology</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(e2) Natural environment and human-made changes to environment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(e3) Support and</td>
<td>100% (1)</td>
<td>-</td>
</tr>
<tr>
<td>relationships</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(e4) Attitudes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(e5) Services, systems</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>and policies</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Non definable</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not definable</td>
<td>NA (13)</td>
<td>NA (9)</td>
</tr>
<tr>
<td>Not definable Motor</td>
<td>x</td>
<td>33% (3)</td>
</tr>
<tr>
<td>Not definable Balance</td>
<td>0% (2)</td>
<td>0% (2)</td>
</tr>
<tr>
<td>Not definable Development</td>
<td>x</td>
<td>0% (3)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>23% (125)</td>
<td>46% (100)</td>
</tr>
</tbody>
</table>
Ch A p t e R 7

7.3.5 Content analysis of integration of needs and principal problems into the goals

The left-hand panel of Figure 7.4 depicts the distribution of matches between need and goal constructs for the different ICF-CY categories. The figure, and Table 7.2 in more detail, shows that the majority of needs concerned the categories b1 (mental functions), d1 (learning and applying knowledge), d2 (general tasks and demands) and d4 (mobility) with also a considerable number of needs encoded as not definable. Overall, the data do not show a relationship between type of need and integration into treatment goals. Most need-goal matches (24% of the 29 matches) fell within category d1 (learning and applying knowledge). Remarkably, only 3 of the 29 need constructs (10%) in category d4 (mobility) matched a goal construct.

The right-hand panel of Figure 7.4 shows the distribution of matches between problem and goal constructs per ICF-CY category (see Table 7.2 for percentages and numbers). Principal problems mostly pertained to category b1 (mental functions) and this was also the category in which most matches were found (35% of all 46 goal-problem matches). Again, the data per ICF-CY problem category (Table 7.2 and Fig. 7.4) do not show a clear preference for specific categories being integrated into the treatment goals.

Figure 7.3. Distribution of matches and mismatches of goal constructs with need and problem constructs per ICF-CY category

7.3.5 Content analysis of integration of needs and principal problems into the goals
The results in the current study showed that in clinical practice the integration of the needs and problems of children with cerebral palsy into their shared rehabilitation goals was not optimal. A remarkable finding, since shared principal goals have widely been recognised as a major prerequisite of and the starting point for effective rehabilitation (Bakheit, 1996; De Moor et al., 1999; DePompei & Williams, 1994; Dule et al., 1999; Fell & Pierce, 1995; Robards, 1994; Roelofsen et al., 2002) and all five participating settings claimed to subscribe the use of the Children’s RAP, which is designed to facilitate this process (Roelofsen, 2001).

Surprisingly, for 24% of the children no shared principal goal and for 12% no needs were formulated in the profiles. This is striking because it has extensively been described that an adequate delineation of the needs for treatment, sound reporting of treatment goals and clearly documented treatment plans are not only essential for proper team collaboration but also enhance treatment outcome (Bakheit, 1996; Monaghan et al., 2005; Rosen et al., 1998).

We found that the parental and professional perspectives seemed reasonably incorporated into the principal treatment goals. For 77% (n=24) of the reports the principal goal represented one

\[
\text{Figure 7.4. Distribution of matches and non-matches between need and principal problem constructs and the goal constructs across the ICF-CY categories}
\]
Chapter 7

or more need or problem construct (or both) reflecting an adequate translation of the formulated perspectives. However, only 23% of all formulated needs were in effect integrated. For the problems as formulated by the professionals, the proportion was higher: 46% of the principal problem constructs matched with a goal construct. For 7 children (23%) we found no matches at all, implying that their goals were not related to either their needs or their problems.

Moreover, because in none of the profiles needs and problems were prioritised, we cannot say whether the formulated goals covered the most relevant or urgent topics. The lack of insight into how and which needs and problems were translated into goals obstructs a well-founded conclusion about the quality of the goal-setting process. Although further research is needed, the striking result that half of the formulated goals were not related to either a need or problem as described in the profile emphasises the need to improve current goal-setting practices in Dutch paediatric rehabilitation.

Our analysis of which needs were incorporated into the principal goals yielded an unexpectedly small number of matches with the goal constructs in the ICF-CY mobility (d4) category: 29 needs pertained to the child’s mobility and only 10% of these were included in a goal construct. This is in sharp contrast to the relatively large volume of matches in the categories b1 (mental functions), d1 (learning and applying knowledge) and d2 (general tasks and demands). Our analysis of the content of goals and the relationship between goals and encoded needs and problems generated few goals in the mobility domain, although the few goals that did fall in this domain (n=5) all related to a specific problem or need (see figure 4). Possibly, the team members had shifted the focus of the treatment for this specific group of children at this stage of their lives. Since all the children were of school age, their educational needs and goals may have been given priority over their mobility needs. Yet, many of the needs the parents reported still concerned their child’s mobility. It would be interesting to investigate why these were not represented in the children’s treatment goals. In addition to the mentioned potential shift of focus from treatment to education, the professionals may also have labelled the mobility needs as inappropriate or unfeasible, possibly attributable to an inadequate parental acceptance of the children’s condition or to impossible goals. To provide more insight into the reasons for not including needs into shared goals, future research should also incorporate an evaluation of the translation process during which needs and problems are interpreted and integrated into goals, the concomitant decision-making process and the way decisions and reasons for decisions are communicated.

Besides the low representation of the mobility domain, our content analysis failed to show whether specific topics or ICF-CY categories were integrated more often than others, which was partly due to the wide distribution of the needs and problems across the ICF-CY categories. However, the goal-content analysis revealed that unrelated goals mostly fell within the environmental factors domain (e1, e2, e3 and e5) and the non-definable categories. A possible explanation for the relatively large amount of unrelated goals in the environmental categories may be that in the formulation of goals preconditions are stipulated for the attainment of the goals that are not mentioned in the need or problem descriptions and it is reasonable to assume that in paediatric rehabilitation these preconditions will mainly be related to the child’s environmental context. This is illustrated by the following example of goal requirements: “The family system, education professionals and therapists provide Tim with structure and support to enable him to develop self-confidence in the execution of new tasks”. Additionally, that so many of the unrelated goals matched up with the non-definable categories may be due to goal formulations being too general in nature. Goals like “attuning services”, “changing motor strategies” or “general education” were, for instance, assigned to one
of the non-definable categories. As a result, however, matches with needs or problems failed to appear because the potentially corresponding concepts were defined more specifically and linked to an ICF-CY code that did not represent one of these non-definable categories.

Although too generalised formulations hampered the categorisation of some of the profiles’ needs, problems and goals, the ICF-CY (27) proved valuable in the classification of the content of the concepts and helped determine whether they were integrated into the rehabilitation goals. The interrater reliability scores for the linking procedure in which ICF-CY codes were allocated to the concepts extracted from the Children’s RAPs, were all “fair to good” (Landis & Koch, 1977). The current study illustrates the utility of the ICF-CY in rehabilitation research and provided some usable evidence for the use of the ICF-CY as a tool for clinical documentation and communication. The use of this well-defined, extensive and universally applicable framework is encouraged in the literature and recommended for interdisciplinary disability research (Rosenbaum & Stewart, 2004).

Nevertheless, our evaluations also disclosed some demerits of the classification system. An important restriction in analysing the extent of integration of perspectives with the strict ICF-CY coding method is that the links between preconditions, which are often at the body-function level, and actual activities are not always visible. Even though some needs or problems and goals do not match by ICF-CY code, they may in fact be related. Take, for example, the need termed as “voluntary control over hands” that is encoded as b7 (body-functions domain) and the goal “increase coordination and voluntary control of hand-arm use” that is encoded as d4 (activities-and-participation domain). While the need was translated into a goal defined as a trainable aspect at the body-function level, in our analysis it was denoted as a non-match. Evidently, in our study the basic principle of the ICF methodology to distinguish three levels of human functioning (i.e. body functions and structures, activities and participation, and environmental factors) resulted in matching inaccuracies. Because we wondered whether the ICF-CY method had perhaps been too strict for our research purposes, we conducted a qualitative assessment of the matches and non-matches. The evaluation revealed that in the 225 combinations investigated only 9 ICF-CY non-matches were coded as matches in our qualitative assessment. Hopefully, this already negligible amount of classification errors with the ICF-CY will drop even further now that also in paediatric rehabilitation the rationale of the functional approach (functional physiotherapy) (Ketelaar et al., 2001) is gaining ground. Here, the emphasis is on learning to perform functional tasks rather than attaining normal movement patterns, which automatically directs parents and team members to focus more on the domain the ICF-CY denotes as activities and participation. The Children’s RAP already allows for this approach by its requirement to formulate principal problems in this latter domain (Roelofsen, 2001).

In this light the ICF-CY might even serve as a common framework to help optimise collaborative goal setting. If all team members involved in the care of one particular child were to define its needs and problems in ICF-CY terms, differences between coding strategies or choices would immediately become clear, prompting consensus discussion and priorities to be set because the rehabilitation profile obliges all team members to choose the best-fitting description, i.e. ICF-CY category. Also any discrepancies between team members’ focal points will become apparent (e.g. a retrieval of body functions versus the ability to perform an activity). Non-matches will force the team members to (re)define the definitive goals and decide on one or more mutually acceptable codes, thus obviating deviating interpretations of the same word or phrasing. This is best illustrated by an example. In Tom’s profile the following need is described: “Tom wants to obtain his swimming
The physiotherapist subsequently defined his principal goal as “Help Tom improve the coordination and muscular strength of his legs” and Tom’s teacher wrote: “Help Tom concentrate longer so that he will be able to acquire swimming skills”. Because of their different backgrounds and reference frameworks the two professionals interpreted the problem and thus the solution differently. And although both interpretations are adequate, to optimise collaboration and hence the outcome, Tom’s parents, physiotherapist and teacher will first need to discuss priorities by establishing whether improving Tom’s muscle coordination and strength or his concentration, or a combination of the two, are the main target. If they were to use ICF-CY codes, all parties involved in Tom’s care would speak the same language, which would facilitate communications and thus help expose any dissimilarities in aims or approaches at an early stage.

Some aspects of this study merit further discussion. In this study we solely based our investigations on the needs, problems and goals as they were formulated in the Children’s RAPs. The written information in these profiles may not have completely reflected the clinical practice and the actual way of working, where lack of time may have prevented team members from adequately documenting their activities and updating their records. We did not obtain information on the priorities that were eventually set, nor did we study the actual practices during and involvement of team members in the decision-making and goal-setting processes, or oral communications and resolutions. Although in the actual service delivery the goals may have been better tailored to the children’s needs and principal problems than they were on paper, transparency of the process remains poor. If oral arrangements, priorities and goals are not made explicit in the treatment plans, this will continue to preclude proper evaluation and augmentation of the quality of the care provided. The formulated needs and problems must clearly lead to corresponding goals and the process should be transparent for all parties involved. This process maybe optimised by team members fill out the profiles in a structured, uniform way, guided by clear directions about what should be reported and by whom (Siebes et al., 2007). In this way transparency is warranted and roles and responsibilities are delineated. Also the use of computer software that suppresses the distribution or handling of incomplete records may support this process.

Furthermore, we based our findings on integration of needs and problems into rehabilitation goals on raw text data without investigating whether the issue formulated under the captions; child and parental needs, principal problems and principal goals, complied with the definitions and qualifications given for these concepts in the Children’s RAP manual. As a result we had no insight in the quality of the formulated needs, problems and goals. Since “low quality” or incorrect formulations might influence transparency and the analysis of integration of needs and problems into the goals, future research should incorporate such quality assessments.

A way to improve goal-setting procedures would be to optimise the phrasing and documentation in the children’s rehabilitation profiles. To enhance the formulation of (parental) needs, for instance, the Canadian Occupational Performance Measure (COPM) (Law et al., 1990) could be a very useful tool. This semi-structured interview was originally developed to help occupational therapists identify work-related performance problems in adults and define treatment goals and is now also used in paediatric rehabilitation to assist goal setting (Verkerk et al., 2006). By expanding the focus of the interview, multidisciplinary teams can use the COPM to delineate the needs and priorities of both the child and its parents (Siebes et al., 2007). To improve the formulation of goals the often-cited Goal Attainment Scaling (GAS) (Kiresuk et al., 1994;Kiresuk & Sherman, 1968) is recommended. It is specifically designed for use in settings in which explicit goals need to be set jointly (i.e. by professional team members, child and parents). In the GAS the expected
outcomes are defined, the degree of achievement of each goal is evaluated, distinguishing, for instance, between partial completion and additional achievement, and a time frame for a review of achievements is set. Treatment goals thus become explicit and measurable objectives, which improves the transparency and interpretability of the goals proposed by the parents and the professionals (Siebes et al., 2007). We feel that if these two instruments are used when completing the Children’s RAPs, they may improve the quality and transparency of the reports and augment the goal-setting process.

7.5 Clinical Messages

- Integration of the needs and principal problems of children with cerebral palsy into their rehabilitation goals was not optimal.
- The integration was difficult to objectify because needs, problems and goals were poorly documented and never prioritised
- The ICF-CY tends to be a reliable instrument for an objective evaluation of goal setting in clinical practice.

7.6 Acknowledgements

The current study was conducted as part of the PERRIN (Paediatric Rehabilitation Research in the Netherlands) research programme. The authors are indebted to all the families, the five rehabilitation centres Center for rehabilitation Beatrixoord, Het Roessingh, Revalidatie Friesland, Blixembosch and Sophia Revalidatie as well as the schools for special education Mytylschool Prins Johan Friso, Educational centre Het Roessingh, School Lyndensteyn, Mytylschool Eindhoven and Mytylschool de Piramide for taking part in the study. We thank Griese Olijve for her help with the data collection and her commitment to the ProCP study. We gratefully acknowledge the Netherlands Organization for Health Research and Development (grant number 1435.0011) and the National Rehabilitation Fund for funding the research project as well as for their co-operation.

7.7 References


### Appendix 7.1 Flow diagram of the data collection and data organization

<table>
<thead>
<tr>
<th>Steps</th>
<th>Example (Jack)</th>
</tr>
</thead>
</table>
| **Step 1.** Extraction of verbatim notes from Children’s RAP Raw text under the following headings were extracted: Child or parental needs, principal problem and principal goal. | **Data Source: Children’s RAP**  
- **Child and/or parental needs**  
  “Jack would like to be able to transfer himself without help at home, at school, everywhere. His parents would like to place priority on Jack being able to dress and undress on his own”  
- **Principal problem**  
  “Jack has a diplegia which expresses oneself in problems with independent mobility as well Jack experience problems according to bad sense of hearing”  
- **Principal goal**  
  “Jack trains his balance skills and is able to dress himself on his own” |
| **Step 2.** Organization of raw text data in text elements describing a single issue further referred to as “concepts.” | **Child and/or parental needs**  
1. Jack would like to be able to transfer himself without help at home, at school, everywhere  
2. His parents would like to place priority on Jack being able to dress and undress on his own  
**Principal problem**  
1. Diplegia  
2. Problems with independent mobility  
3. Bad sense of hearing  
**Principal goal**  
1. Jack trains his balance skills  
2. Jack is able to dress himself on his own |
| **Step 3.** Two raters independently classified all concepts in the ICF-CY (three-digit codes). A single concept can be classified in more than one ICF-CY category. ICF-CY classifications of needs, problems and goals are further referred to as “(ICF-CY) constructs.” | **Child and/or parental needs**  
1. Jack would like to be able to transfer himself without help at home, at school, everywhere (D460)  
2. His parents would like to place priority on Jack being able to dress and undress on his own (D2 + D540)  
**Principal problem**  
1. Diplegia (B7353)  
2. Problems with independent mobility (D4)  
3. Bad sense of hearing (B230)  
**Principal goal**  
1. Jack trains his balance skills (ND balance)  
2. Jack is able to dress himself on his own (D2 + D540) |
| **Step 4.** Determination of matches by means of ICF-CY-code comparison on the category level (1 digit) in the following combinations: Needs-goals; problems-goals; goals-needs and goals-problems. | Need-goal:  
1. D4-x = no match  
2. D2-D2 = match  
3. D5-D5 = match  
Problem-goal:  
1. B7-x = no match  
2. D4-x = no match  
3. B2-x = no match  
Goal-need:  
1. ND balance-x = no match  
2. D2-D2 = match  
3. D5-D5 = match  
Goal-Problem:  
1. ND balance-x = no match  
2. D2-x = no match  
3. D5-x = no match |