



## CASE STUDY

# Simultaneous development and implementation of the Children's Rehabilitation Activities Profile: a communication instrument for pediatric rehabilitation

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## Abstract

**Purpose:** To describe the methods used for the development and implementation of the Rehabilitation Activities Profile for Children (Children's RAP), an instrument to structure information for team conferences.

**Methods:** Our strategy consisted of nine steps: (1) survey in clinical practice; (2) literature search; (3) formation of a national study group; (4) development of specifications and a national draft; (5) development of local drafts; (6) integration of local drafts; (7) consultation of users and experts; (8) national conference; and (9) assessment of user experience.

**Results:** The final version of the Children's RAP consists of three sections: (1) basic information about the child and its proxies; (2) present situation and needs of the child and its proxies; and (3) conclusions of the team conference. User satisfaction ranged from adequate to good. The Children's RAP is currently used in 53% of the Dutch pediatric rehabilitation centres.

**Conclusion:** The methods used guarantee an optimal involvement of users, experts and literature. With these methods it was possible to develop an instrument which is widely accepted and implemented in clinical practice.

## Introduction

The aim of pediatric rehabilitation is to optimize the development of the child, given the capacities of the child and its family.<sup>1,2</sup> This requires an adequate knowledge of the impairments and the pathological process, as well as the consequences of these impairments for the development of the child and for the family.<sup>2,3</sup> In order to address the multiple problems of the child, a team of specialists is often involved in the rehabilitation process. Team members meet regularly during team conferences to determine the rehabilitation plan for the child, and for this purpose adequate information is needed. Several instruments are used to structure this information.<sup>4</sup> However, all these instruments were constructed for the rehabilitation of adults.

The Rehabilitation Activities Profile (RAP) has recently been developed for adult rehabilitation in our department.<sup>3</sup> Following the development of the RAP, pediatric rehabilitation physicians requested an adaptation of this instrument, to be used for the rehabilitation of children. However, implementation of the RAP in adult rehabilitation had failed to demonstrate any improvement in satisfaction with regard to team conferences.<sup>5</sup> It was assumed that top-down implementation of a fixed instrument, as had been the case with the RAP for adults, probably did not facilitate acceptance of the instrument. Therefore, we decided to closely involve

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users in the development and implementation of the Children's RAP.

The present article describes the methods used, and also the results, in terms of diffusion and satisfaction.

**Methods**

Our strategy of development and implementation consisted of the following nine steps (table 1).<sup>6-8</sup>

STEP 1: SURVEY IN CLINICAL PRACTICE

In order to investigate whether there was a need for an instrument to structure team conferences in pediatric rehabilitation, in April 1996 an open questionnaire was sent to one rehabilitation physician in each Dutch pediatric rehabilitation setting (n = 32).

Professionals from 20 settings (63%) responded to the survey. All respondents stated that their team conferences were at least reasonably effective. However, all except one indicated that the team conferences could be improved. The most frequently mentioned suggestions for improvement were the use of a structured format for written reports (n = 8) and the development of a structure to enable the team conference to focus on major problems (n = 10).<sup>9</sup>

From the results of the survey we concluded that adaptation of the RAP for use in pediatric rehabilitation, would meet existing needs.

STEP 2: LITERATURE SEARCH

A literature search was carried out to identify any available scientific knowledge about the information needed for team conferences in pediatric rehabilitation

(January–April 1996). The Medline and PsychLIT databases were used to search for instruments to structure information in pediatric rehabilitation and functional assessment scales for children (from 1985 onwards). The key words 'functional assessment', 'disability evaluation' and 'rehabilitation' were used. In addition, references of reviews and local instruments already used in the Netherlands to structure information in both pediatric and adult rehabilitation were gathered.

The literature search did not yield instruments which could be used to structure team conferences or reports in pediatric rehabilitation, but it did identify several functional assessment scales for children. These scales are used mainly to evaluate interventions<sup>10-12</sup> or to discriminate between children according to their functional level.<sup>13-17</sup> In addition, a number of scales were identified which are used to assess several aspects of the functioning of a child, mainly motor functioning.<sup>18-25</sup> Several publications reported use of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) to assess the functioning of children.<sup>26-30</sup>

The scales found in the literature search, the RAP for adults,<sup>3</sup> the ICIDH<sup>26</sup> and adapted trials of the ICIDH,<sup>31</sup> five local instruments which were used in Dutch pediatric rehabilitation, and similar instruments used in adult rehabilitation,<sup>4, 32</sup> were examined for information needed for team conferences in pediatric rehabilitation. This assessment resulted in a first proposal for the Children's RAP.

STEP 3: FORMATION OF A NATIONAL STUDY GROUP

A national study group was formed to enhance support in the field (April 1996). Together with the questionnaire (step 1), each setting (n = 32) was invited to

**Table 1** The steps of the development and implementation of the Children's Rehabilitation Activities Profile

<i>Steps</i>	<i>Goal</i>
1) Survey in clinical practice	Assessing needs of the teams
2) Literature search	Assessing scientific knowledge
3) Formation of a national study group	Enhancing support in the field
4) Development of specifications and a national draft	Formulation of specifications and the first national draft of the instrument by the national study group
5) Development of local drafts	Evaluation of the national draft and further local development by the local study groups
6) Integration of local drafts	Realization by the researcher (EER) of a second national draft, suitable for clinical practice
7) Consultation of users and experts	Fine-tuning of the second national draft, resulting in the final instrument
8) National conference	Ensuring widespread publicity of the instrument
9) Assessment of user experience	Evaluation of the instrument

delegate one or two representatives in the national study. It was proposed to delegate one rehabilitation physician or pedagogue and one representative of the other disciplines.

All respondents to the questionnaire agreed to participate in the national study group. There were 10 non-respondents, seven of whom were not interested in the study group for various reasons, e.g. no interest in the instrument, no staffing available to participate. The resulting national study group consisted of 29 members (14 rehabilitation physicians, 8 physiotherapists, 4 psychologists, 1 speech therapist, 1 occupational therapist and 1 team manager) representing 20 Dutch pediatric rehabilitation settings.

The national study group met twice a year (six times in total) to discuss the development of the instrument and the experiences of the users.

STEP 4: DEVELOPMENT OF SPECIFICATIONS AND A NATIONAL DRAFT

The national study group determined the specifications of the instrument and reached consensus about the information to be included in it (April–September 1996).

To determine the specifications, the national study group members were asked to define their expectations of the Children’s RAP. For the development of the national draft, the proposal resulting from the literature search (step 2) was presented to the group. This proposal was then discussed and adjusted for relevance to clinical practice.

After two meetings, the specifications and the national draft were finalized in September 1996 (table 2).

STEP 5: DEVELOPMENT OF LOCAL DRAFTS

To evaluate feasibility in practice and to further develop the Children’s RAP, the national draft was implemented in seven pediatric teams of five rehabilitation centres who wished to participate in the project (September 1996–April 1998). The characteristics of the teams are summarized in table 3. The treatment provided by these teams covered all categories of children in pediatric rehabilitation. A two year project was initiated in these experimental teams. Team G (centre 5) had already started a project to adapt the RAP for use with children in April 1996, but switched to the national draft of the Children’s RAP in September 1996.

In each centre a local study group was formed to adapt the national draft to local needs. The local study group was also responsible for continuity of the implementation of the Children’s RAP. In these local study groups all key disciplines were represented. Group sizes ranged from five (centre 3: team C) to 10 (centre 4: teams D, E, F) members.

Using the domains of the national draft to describe the abilities of the child and its proxies, each local study group selected relevant abilities (items) for each domain. Two centres (2 and 4: teams B and D, E, F, respectively) developed the items independently over a period of nine and 13 months, respectively. One centre (5: team G) retained the items of the RAP for adults and developed

**Table 2** Specifications and the first national draft of the Children’s Rehabilitation Activities Profile developed by the national study group in September 1996

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Specifications of the Children’s RAP	
	containing the minimum set of data needed to formulate and evaluate goals
	adaptability to local needs
	description of the child and its proxies
	description of needs of the child and its proxies
	focus on abilities instead of disabilities and handicaps
	comprehensible and relevant for all team members and for parents
<i>First national draft of the Children’s RAP</i>	
Information is organized in three sections:	
Section 1	Basic information about child and proxies
	medical diagnosis and prognosis; family situation; needs of the child and its proxies
Section 2	Present situation of child and proxies
	6 domains describing abilities of the child: (1) communication; (2) mobility; (3) personal care; (4) occupation; (5) cognitive and learning abilities; (6) social-emotional functioning
	1 domain describing the abilities of the proxies
Section 3	Conclusions of the team conference
	principal problem; hindering factors; treatment goals

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**Table 3** Characteristics of the experimental teams

Centre	Team	Number of team members <sup>1</sup>	Treatment <sup>2</sup>	Age of the children treated
1	A	15	out	0–18 (mostly 0–4)
2	B	16	out/day	0–18
3	C	15	out/in	4–16
4	D	25	out/day	0–18 (out) + 0–4 (day)
	E	23	day	4–18
	F	15	in	0–18
5	G	15	out/day	0–18 (out) + 4–18 (day, only multiple complex disabled children)

<sup>1</sup>excluding nurses and teachers

<sup>2</sup>out = outpatient treatment; day = day-care-treatment in special schools or in early intervention groups linked to the rehabilitation centre; in = in-patient treatment.

supplementary items for pediatric rehabilitation. Two other centres (1 and 3: teams A and C) asked the researcher (EER) to suggest items and subsequently adapted the item-proposal to their own needs.

A manual for the use of the Children's RAP was developed by the researcher. This manual was subsequently discussed with the local study groups.

During the development of the local drafts the national study group was consulted by the local study groups about the terminology and sequence of the second section (present situation of child and proxies), and the extension of the third section of the Children's RAP (conclusions of the team conference) (April 1997). In addition, the trainer who had introduced the Children's RAP to two of the experimental teams (teams C and G), and to four other interested teams, was consulted by the researcher several times to discuss the experiences gained and to determine the definitions of the terms to be used in the Children's RAP. In April 1998, five local drafts were available, all of which were more detailed than the national draft (step 4).

**STEP 6: INTEGRATION OF LOCAL DRAFTS**

In order to consolidate the information into one single instrument, the five local drafts were integrated by the researcher (EER) in April 1998. At that time, four teams were using the national draft, supplemented with locally developed items. One centre (4: teams D, E and F) was only using the domains and items to describe the abilities of the child and its proxies. This centre did not describe the needs of the child and its proxies and did not use the third section (conclusions of the team conference). Locally developed items were used for 26 months (team G), 16 months (teams A and C), 2 months (teams D, E and F), or only occasionally (team B).

As differences between the local drafts existed only in the second section (present situation of child and

proxies), it was decided to concentrate further development on the standardization of the domains and the items contained in this section. The differences mainly concerned the domains of 'cognitive and learning abilities' and 'social-emotional functioning'. In these domains, both the terminology and the categorization of the items differed (e.g. development of personality, sexuality and social functioning (domain 'social-emotional functioning'; team B) versus expressing needs, expressing feelings, taking initiative, dealing with changes and dealing with others (domain 'social-emotional functioning'; teams D, E and F)). Moreover, items included in these domains sometimes concerned impairments, instead of abilities (e.g. acquiring information; domain 'cognitive and learning abilities'). In the other domains there were only minor differences, concerning the removal of items (e.g. sleeping; domain 'personal care'), splitting or combining items (e.g. moving around versus moving around inside and moving around outside; domain 'movement abilities') and terminology (e.g. expressing versus clarifying your aim; domain 'communication').

To integrate the local drafts, the items they contained were compared to the specifications (step 4), the ICIDH-2,<sup>33</sup> the RAP for adults and the other instruments identified in the literature search (step 1). In addition, the domain 'motor abilities' was renamed 'movement abilities' and the domain 'cognitive and learning abilities' was renamed 'learning abilities', to stress the functional aspects. As a result of this step, a second national draft was proposed by the researcher, which was adapted and further detailed as a result of the experiences gained in clinical practice.

**STEP 7: CONSULTATION OF USERS AND EXPERTS**

To achieve a high level of professional acceptance and feasibility, the second national draft was presented to

the local study groups twice (a total of 33 persons), and also to a larger group twice (a total of 55 persons: 19 members of the national study group, 10 members of both national and local study groups, 23 members of local study groups, 3 professionals using the Children's RAP in other teams) (April–October 1998). These persons were asked for written comments. In the same period, an oral consultation was held with the national study group (June 1998). Together, the experimental teams organized an expert meeting to discuss the domains of 'learning abilities' and 'social-emotional functioning' (4 social workers, 3 psychologists and 10 other professionals) (September 1998).

During this expert meeting, a new categorization was proposed for the domain of 'learning abilities', stressing abilities instead of impairments. In the domain of 'social-emotional functioning' the five existing items were sub-divided into nine items. Furthermore, terms were introduced which would be more comprehensive for parents.

In October 1998, the second section of the Children's RAP (present situation of child and proxies) was provided with nationally standardized domains and items. Consensus was reached between the local study groups about all but one domain ('social-emotional functioning'). For this domain the advice of the expert meeting was followed, and some items were sub-divided, but the option to retain the non-sub-divided items was also included.

#### STEP 8: NATIONAL CONFERENCE

The Children's RAP was presented to the Dutch pediatric rehabilitation centres during a national conference in November 1998 to ensure widespread publicity. The interest shown in the conference was overwhelming: 28 (out of 32) pediatric rehabilitation settings and 16 (out of 34) special schools for physically disabled children were represented by a total of 238 persons.

#### STEP 9: ASSESSMENT OF USER EXPERIENCE

To evaluate the instrument, experiences of the users were assessed two and a half years after the start of the project in the experimental teams (April–October 1999).

A questionnaire was distributed to all members of the experimental teams, except for team G, which had started earlier than the other experimental teams. As a result this team did not participate in the evaluation of the Children's RAP. Team members ( $n = 106$ ) were asked to judge the Children's RAP as a reporting system

and as a structure for team conferences using a 1 to 10-point interval scale (1 = very bad, 10 = excellent).

## Results

The final model of the Children's RAP structures the information needed to determine the rehabilitation plan for a child. This information is arranged in three sections: (1) basic information about the child and its proxies; (2) present situation of the child and its proxies; and (3) conclusions of the team conference (table 4).

In order to formulate a treatment plan, basic information about the child and its proxies is first needed (section 1). Secondly, information about the present situation of the child and its proxies should be available (section 2). For the description of the present situation of the child information is divided in an impairment section and an abilities section. As the rehabilitation team focuses on the abilities of the child, this section is further detailed with nationally standardized domains and items. In addition to a description of the child, a description of the proxies has also been added, because of the treatment aims at optimizing the development of the child, given the capacities of the child and its proxies. Furthermore, the needs of the child and its proxies have to be described in this section, as these form the basis for further treatment. In the third section of the Children's RAP, the conclusions of the team conference are described. These conclusions consist of a shared problem analysis and a shared goal, as well as subsequent rehabilitation goals for the individual professionals.

The Children's RAP can be used to structure reports for the team conference as well as to structure the team conference itself. The Children's RAP is a framework which can be adapted to the local needs of the teams, and a manual is available.

The median judgements of the experimental teams about the Children's RAP as a reporting system and as a structure for team conferences (step 9) ranged from 6 (adequate) to 8 (good) (table 5).

Five years after the initiation of the project (October 2000), the Children's RAP is still used by the experimental teams. Moreover, the Children's RAP is used in 17 settings (including the experimental teams) (53% of the Dutch pediatric rehabilitation settings). More settings ( $n = 11$ ) are currently investigating the possibilities for training and implementation of the Children's RAP. The Children's RAP is expected to be used in 88% of the Dutch pediatric rehabilitation settings within 3 years.

*Children's Rehabilitation Activities Profile*

**Table 4** Final version of the Children's Rehabilitation Activities Profile<sup>1</sup>

<i>1. Basic information about child and proxies</i>	<i>2. Present situation of child and proxies</i>	<i>3. Conclusions of the team conference</i>
<i>Basic information</i>	<i>Needs</i>	<i>Principal problem</i>
Personal details	Child	Hindering factors
Family situation	Proxies	Facilitating factors
Educational situation of the child		
Adaptations/adapted living		
Accommodation/aids etc.		
	<i>Present situation<sup>2</sup></i>	<i>Principal goal</i>
	<i>Child</i>	
	Impairments	
	<i>Abilities</i>	
	– movement abilities	
	– learning abilities	
	– communication	
	– personal care	
	– social-emotional functioning	
	– occupation	
	<i>Proxies</i>	
	Abilities of	
	– family	
	– adults	
	– peers	
<i>Diagnosis</i>		<i>Treatment goals</i>
Medical diagnosis		
Medical information		
		<i>Child</i>
		(goal/method/responsible person/term)
		categorized in domains of abilities
		<i>Proxies</i>
		(goal/method/responsible person/term)
		categorized in domains of abilities

<sup>1</sup>The space in this framework does not determine the space which an aspect is allocated in the report.

<sup>2</sup>This section contains nationally standardized items.

**Table 5** User experience with the Children's Rehabilitation Activities Profile<sup>1</sup>

<i>Teams</i>	<i>A</i>	<i>B</i>	<i>C</i>	<i>D*</i>	<i>E*</i>	<i>F*</i>
Number of respondents	12	12	13	21	17	11
Judgement about the Children's RAP as a reporting system#						
25 <sup>th</sup> percentile	7	6	7	6	7	6
Median	8	6	7	8	7	7
75 <sup>th</sup> percentile	8	7	8	8	8	8
Judgement about the Children's RAP as a structuring method for team conferences#						
25 <sup>th</sup> percentile	6	6	6	6	6	7
Median	7	6	7	7	7	7
75 <sup>th</sup> percentile	8	8	8	7	8	8

<sup>1</sup>No information available from team G

\*Teams D, E, and F only used the categorization of the abilities of the child and its proxies (second section of the Children's RAP) for reporting and team conferences at the moment of evaluation.

#Scores read: 1 = very bad, 2 = bad, 3 = very inadequate, 4 = inadequate, 5 = almost adequate, 6 = adequate, 7 = more than adequate, 8 = good, 9 = very good, 10 = excellent.

## Discussion

### METHODS OF DEVELOPMENT

With the methods described above, it proved to be possible to develop a nationally accepted instrument to structure team conferences in pediatric rehabilitation. The methods guarantee the input from users, experts, and literature, thus combining the advantages of each individual source and avoiding biases.<sup>6, 34–36</sup> Input from users was guaranteed by development within the teams, resulting in an instrument which is close to clinical needs and feasible in daily practice. The experts represented in the national study group checked that local developments fulfilled national needs. Input from the literature was guaranteed by the researcher (EER) during the literature study and the comparison of user expertise contained in local drafts with the literature.

According to Grol *et al.*<sup>6</sup> an instrument should meet the following criteria to be accepted and to be implemented in clinical practice: (1) based on scientific evidence; (2) reproducible; (3) feasible; (4) flexible; (5) specific and differentiated; (6) understandable; (7) didactic; and (8) attractive. The Children's RAP meets these criteria as follows: Scientific input was guaranteed by the involvement of the researcher and will be monitored by further evaluation of the instrument (1). As local drafts only differed on minor points, the instrument is reproducible (2). Involvement of users guaranteed feasibility (3). The Children's RAP is a flexible instrument, allowing for local adaptations and specifications (4, 5). Discussions about the terminology and layout of both the instrument and the manual resulted in an understandable, didactic and attractive instrument (6–8).

Furthermore, the composition of the development group and the processes of development influence the quality of an instrument.<sup>36</sup> During the development of the Children's RAP, all key disciplines were represented in the local study groups, resulting in an instrument which can be used by all disciplines. In addition, during the development of the national draft (step 7) both oral and written comments were obtained. Oral comments enhance the exchange of opinions, making it easier to reach a consensus. Written comments result in anonymous opinions, free from group influences.<sup>6, 36</sup>

The resulting Children's RAP is a nationally standardized instrument based on consensus among users and experts, close to clinical practice and adaptive to local needs. However, the methods used to develop the Children's RAP were time-consuming. It took two years to complete the development. Furthermore, the

national study group was formed voluntarily, resulting in a motivated group. It is therefore possible that the opinions of more critical persons in the field of rehabilitation were not heard. In addition, the experiences of the children and their parents have not yet been taken into account.

### CONTENT OF THE CHILDREN'S RAP

During the development of the Children's RAP, the teams focused on standardization of the description of the present situation of the child and its proxies (second section of the Children's RAP). However, the experimental teams finally concluded that the exact definition of the items was of minor importance, compared to the overall framework of the instrument.

Differences of opinion between the experimental teams did not concern the framework of the Children's RAP, but mainly the standardization of the items of the domains of 'learning abilities' and 'social-emotional functioning'. Items in these domains are more difficult to observe, and concern less concrete behaviours compared to the other domains. Development of these domains took a lot of time, compared with the other domains. Finally, locally developed items tended to be named according to the theoretical framework of the psychosocial disciplines represented in the local study group. This resulted in differences between locally developed items. Discussions on the domain of 'learning abilities' concentrated on the question of whether an item was an impairment or an ability. Items included in the final version were in accordance with the items of the domain of 'learning abilities' in the ICDH-2.<sup>33</sup> Discussions on the domain of 'social-emotional behaviour' mainly concerned the level of sub-dividing items. The first local proposals regarding this domain determined two items: 'social functioning' and 'emotional functioning'. The domain finally consisted of nine items. Before the introduction of the Children's RAP, narrative reports were made to describe the behaviour of the child. Sub-dividing the observation into nine items resulted in a more business-like report which did not agree with usual practice in psychosocial disciplines. However, according to the expert meeting (step 7), the nine items in the final version resulted in a representative and useful checklist for reporting in this domain.

### ACCEPTANCE IN THE FIELD

According to the high percentage of centres implementing the Children's RAP and the favourable judge-

ment of the users, described above (step 8, 9), acceptance in the field is high. Acceptance is assumed to be enhanced by the involvement of professionals participating in experimental teams and by the involvement of a national study group.<sup>6, 34, 35, 37</sup> In addition to the development strategy, the following factors are also assumed to have influenced acceptance in a positive way. Firstly, the Children's RAP followed local initiatives to enhance a patient-oriented and goal-oriented approach in pediatric rehabilitation. Secondly, during the development phase, newsletters were sent to all Dutch pediatric rehabilitation physicians and other interested people, and professional magazines published articles about the Children's RAP regularly. These publications arose interest and promoted insight into the process of development. Thirdly, the final Children's RAP was disseminated extensively. At the national conference all attendants received the Children's RAP and the manual for users, and it was freely available for all other interested people. Finally, pediatric rehabilitation physicians were looking for a framework which would confirm the specific identity of pediatric rehabilitation and distinguish it from rehabilitation for adults. The Children's RAP is intended to provide the field of pediatric rehabilitation with this framework. Therefore, rehabilitation physicians strongly supported the development of the Children's RAP.

#### FURTHER DEVELOPMENT OF THE CHILDREN'S RAP

In future, the content of the Children's RAP should be reviewed regularly, and the experiences of new users should be taken into account. In particular, experiences with the implementation of the Children's RAP in special schools for physically disabled children, linked to rehabilitation centres, should be followed closely. The experiences of the children and their parents should be incorporated. Moreover, the short-term and long-term effects of using the Children's RAP should also be investigated.

To facilitate further implementation of the Children's RAP, the national study group should represent more disciplines and include representatives from special schools. The goals of the national study group should be extended to provide training for junior and senior users. In addition, attention should be paid to informing professionals, other than rehabilitation physicians, as well as the managers of the rehabilitation centres. Finally, educational courses for rehabilitation professionals should include the Children's RAP in their curriculum.

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