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

Nijhuis, Bianca Gertruda Johanna

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Chapter 1

Paediatric rehabilitation focuses on children with a temporary or sustained primary motor disturbance. It aims at restoring the child’s (potentially) disturbed interaction with its environment and at achieving an optimal level of autonomy for the child. Paediatric rehabilitative care inherently has a pedagogic scope as it fulfils a major function in the rearing of the child and hence encompasses both the physical, psychosocial and educational development of the child and the impact on its family (Meihuizen-de Regt et al., 2003). Since most children seen in paediatric rehabilitation have a chronic condition (e.g. cerebral palsy), this implies continued treatment in different developmental stages in the child’s life. The three key elements that make up the rehabilitation process are rehabilitation treatment, education at a school (for special education) and child-rearing at home.

Because the child’s needs and problems can be complex and change over time, a variety of professionals from different organizations are involved in the provision of health care and education involving both the child and its parents. It is widely acknowledged that close collaboration between these professionals (Bakheit, 1996; Barnes & Turner, 2001; Hinojosa et al., 2001; Lyon & Lyon, 1980; Radan, 1997; Robards, 1994; Rosen et al., 1998; Thylefors et al., 2000; Yerbury, 1997) and the parents (DePompei & Williams, 1994; Hostler, 1999; King et al., 1997; King et al., 2004; Rosenbaum et al., 1998) is indispensable and of crucial importance to the quality of paediatric health care. Yet, although the need for close collaboration between the parents, children and professionals in specialised teams has become a well-established view both in the literature and in the clinical practice, there is still a gap in our knowledge about how existing team approaches are being implemented in clinical practice. In other words, there is a lack of information on how child rehabilitation professionals and parents actually cooperate. To bridge this gap in our knowledge and to explore deficiencies in and possibilities to improve current practices in Dutch paediatric rehabilitation, this thesis describes how today the various parties communicate and work together in the care for children with cerebral palsy. Which factors or elements are important when defining or describing collaborative team practices in paediatric rehabilitation? How is team collaboration organised in actual practice? Are services family-centred and how are (treatment) goals set?

This introductory chapter provides a brief background on teamwork in paediatric rehabilitation in the Netherlands. First, a short description of current practices is given, with a focus on the organizational structure of and recent developments in teamwork in Dutch paediatric rehabilitation. Subsequently, a short description of the research project occasioning this thesis is provided. The chapter concludes with an outline of the individual studies of the project.

1.1 Paediatric rehabilitation in the Netherlands

In the Netherlands paediatric rehabilitation services are delivered in both clinical (inpatient) and day-care (outpatient) settings. The 23 national rehabilitation centres with paediatric facilities and the rehabilitation departments of all medium-sized and larger hospitals offer treatment on an outpatient basis only. For inpatient treatment children can be referred to one of nine specialised, regional rehabilitation centres. Each year 9000 children are treated on an outpatient basis and 300 children on an inpatient basis (Revalidatie Nederland, 2005).

As a rule, paediatric rehabilitation is targeted at children between the ages of 0 and 20 years although in daily practice the upper age limit is determined by the young adult’s social situation and depends on whether paediatric or adult care is the best option (Meihuizen-de Regt et al.,
2003). Services for the youngest children are mostly provided by therapists working in a community setting, often combined with outpatient visits to a consultant paediatrician specialised in paediatric rehabilitation medicine, with or without additive specialised support from the rehabilitation centre. Preschool children (1 to 4 years) with complex motor problems, which are often accompanied by significant delays in other developmental domains as well, can visit specialised therapeutic, classroom-based toddler programmes (Hendriks, 2001) the rehabilitation centre offers several days a week. In addition to therapeutic activities, the programme includes medical care, technical support, developmental programming by an infant teacher, and parental and family guidance. Once the children have reached school age, they are either referred to mainstream schools or to schools for special education. Preferably, the children will attend mainstream schools that may engage the services of a local school for special education to support general educational requirements. When disabilities are more complex and children need care and nursing on a daily basis, they will be enrolled in schools for special education.

More than half of the children undergoing treatment in Dutch paediatric rehabilitation have been diagnosed with cerebral palsy (CP) and of these children the majority attend schools that exclusively provide education adapted to children with disabilities. These schools for special education, in the Netherlands called Mytyl and Tytyl based on a fairytale by Maurice Maeterlinck (1908), often have close connections with the local rehabilitation centre enabling the rehabilitation specialists and teachers to jointly decide on the nature of the care each child is to receive.

However, the ideas and priorities of the various professionals involved in the child's rehabilitation and education may differ according to the goals they have set for the child at any given time. The school may, for example, have opted to specifically focus on teaching the child to learn to read while the rehabilitation centre may have recommended surgery to correct deformities in one of the child's legs, thus frustrating the schools plans and delaying the child's intellectual development. This example clarifies the need for integration of services and jointly established treatment plans. In the Netherlands the provision of comprehensive and integrated care is high on the agenda, both in rehabilitation and educational practices as well as in research. The Dutch Council of Health Research (RGO, 1997) has advocated close collaboration between the rehabilitation centres, schools for special education and parents by describing paediatric rehabilitation as “oriented on children with physical disabilities in which medical, sociological and psychological disciplines are integrated”. This desired integration of services is also captured by the motto “One child, one plan” featuring on the website of Revalidatie Nederland1. Because the national rehabilitation centres and schools for special education are separate entities residing under different ministerial departments and thus subject to different funding and legislation, integration and co-ordination of services is crucial to ensure optimal and comprehensive treatment and support for both the children and their parents. Besides the rehabilitation professionals and special education professionals the third main stakeholder group is the child’s parents. Therefore, in the “One child, one plan” strategy educational and rehabilitation goals as well as important characteristics of the home environment need to be integrated and the three stakeholders need to be able to interchange priorities. At times rehabilitation should be given priority over educational objectives and at other times learning should prevail with rehabilitation activities taking a back seat for the time being.

1 Revalidatie Nederland is the official organization for rehabilitation services in the Netherlands
To optimise the planning, delivery and efficacy of integrated rehabilitation programmes in the Netherlands a communication instrument called the Rehabilitation Activities Profile for Children or Children’s RAP (Roelofsen et al., 2001) has been introduced and implemented by rehabilitation services nationwide. This communication instrument, partly based on the International Classification of Impairments, Disabilities and Handicaps (ICIDH)(World Health Organization, 1980) provides the parents and professionals with a common language about the abilities of the child and its parents, and a common reference framework about their respective needs, which helps all parties to put the actual problems of the child into words during the (mostly) annual or semi-annual team conferences. Besides the support in formulating actual problems, this communication instrument is intended to serve as a checklist and to help prevent team members forgetting to report on relevant information, or adding irrelevant information (Roelofsen et al., 2002). Furthermore, the instrument directs the team towards the formulation of interdisciplinary rehabilitation goals adjusted to the needs of the child and its proxies, and the subsequent evaluation of these goals.

The Children’s RAP was primarily developed as a communication instrument for the paediatric rehabilitation sector. Because of the increasing need for co-ordination of services, especially the care provided by rehabilitation centre and schools for special education, various collective paediatric services have started to adapt the profile to accommodate and fine-tune the plans and programmes of the various disciplines from rehabilitation centre and school for special education. Yet, we have no insight into the exact status of the implementation of such integrated rehabilitation plans and the (combined) use of the Children’s RAP in the centres and schools at this point in time.

During the time the Children’s RAP was developed and implemented, the ICIDH framework (World Health Organization, 1980) has been revised. From emphasizing people’s disabilities (ICIDH), the focus now is on their level of health (ICF). The ICF (International Classification of Functioning, Disability and Health; World health organization, 2001) provides a standard language and framework for the description of health and health related status in order to improve communication between different users, such as health care workers, researchers, policy makers and the people with disabilities themselves. Because the original ICF did not adequately capture the functional characteristics specific to the developing child the ICF for children and youths (ICF-CY) (World Health Organization, 2007) was developed. Like the ICF, the ICF-CY provides a systematic coding scheme that classifies the level of health of a child in the domains; body functions and structures, activities and participation, environmental factors and personal factors.

Along with the increasing implementation of “Family-Centred Care” (FCC) (King et al., 2004;Rosenbaum et al., 1998) in other countries, the active involvement of parents and family of children with disabilities in the service delivery and decision-making process has increasingly become an important aspect of care policy, quality assessments and research in the Netherlands. Parent involvement and FCC have been described as key issues in various reports on the perspectives and policies in Dutch paediatric rehabilitation (Dutch Council of Health Research, 1997;Siebes, 2006;Stichting toekomstscenario’s Gezondheidszorg, 2000;Stichting toekomstscenario’s Gezondheidszorg, 2001;VRA Kinderplatform et al., 2003;VRIN/VRA, 2000). Besides the views and policies in clinical practice, also health-care laws and regulations are being adapted to allow

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2 “proxies” refers to the child’s parents, siblings, peers and all significant others in the child’s environment.
for the changing relationship between parents and health-care providers. Parents can choose from a wide range of services and arrange to have these paid for directly by health insurance companies (van Schie et al., 2004). More recently they can apply for a so-called PGB, a personal budget that is managed by the parents and allows them to arrange and purchase the support their child needs in the broadest sense. Nevertheless, although the involvement of parents and family in the care for their children has been high on everyone’s agendas, improvements both at the national and at the institutional level are still warranted. In their final inventory of future innovations, the Dutch Advisory Committee on Paediatric Rehabilitation selected increased attention for parents and the family and appropriate psychosocial support (Stuurgroep Vooronderzoek Landelijk Innovatieprogramma Kinderrevalidatie, 2005) as one of their three main themes for innovation, which should support the optimisation of the family-centredness of current paediatric services.

**What parents and professionals think of the team collaboration in the care for children with cerebral palsy**

“We would really like to work as an interdisciplinary team but for the most part it just doesn’t come about”

“We function as a collaborative, truly cooperative, and goal-oriented team”

“Communication about the children is open but communication about our approach, method of working and goals is more restricted”

“Collaboration does not get off the ground because of time restrictions. Collaboration is restricted to just keeping each other informed”

“There is too little contact time; everybody sticks to his or her own “island of professionalism””

“The distance between the rehabilitation centre and the school for special education restricts collaboration”

“The infrastructure for collaboration is lacking and appointments and consultations are insufficient”

“No adequate distribution of reports”

“Goals are mainly discipline-specific and formulated parallel for each discipline, never collectively”

“There is no collective treatment plan, professionals mainly work from the perspective of their own profession”

“There is too little tuning of services between the rehabilitation centre and the school for special education”

“Parents and school professionals should attend team conferences”
1.2 The PERRIN-ProCP Study

The studies presented in the current thesis are the outcome of the so-called ProCP research project: “The child with Cerebral Palsy: Towards a comprehensive study of the rehabilitation, education at school and rearing at home”, which aimed to describe collaboration practices among the parents and rehabilitation and special-education professionals engaged in the care for children with cerebral palsy.

The ProCP study is one of the six interrelated studies of the PERRIN research programme (PEdiatric Rehabilitation Research in the Netherlands). PERRIN focuses on three major themes: (1) the course and determinants of activities and participation, (2) the development of instruments to measure the levels of functioning, and (3) the description of rehabilitation programmes. Taking the International Classification of Functioning, Disability and Health (ICF) as a conceptual framework, activities and participation are the central concepts in the programme. One of the PERRIN goals is to improve the understanding of the course of activity limitations, participation restrictions and quality of life in children and adolescents with cerebral palsy (CP). Children, adolescents and young adults with CP in the age range of 1 to 24 years are monitored several years. To facilitate an accurate evaluation of their activities and participation, special attention has been paid to the selection and further development of measures that are responsive to changes in personal and social functioning, and to the description of rehabilitation programmes.

The ProCP study was started in 2002 and the results are presented in this thesis. The difficulties professionals and parents encountered in the attainment of the “One, child, one plan” strategy and the principles of FCC formed the basis of our investigations. Although parents, team members and management are all committed to cooperation, coordination and integration of services, implementation of the prescribed approaches (e.g. an interdisciplinary team approach) and collaboration in daily practice proved complex and is as yet not optimal, which is illustrated by the selection of quotes from parents and professionals presented in the text box above. We clearly need to enhance our insights into the characteristics and dynamics of today’s collaboration among parents, rehabilitation professionals and special education professionals if we are to improve current practices and ascertain the critical points (“bottlenecks”) that at present restrict them. In an attempt to provide these insights we started our descriptive study on team collaboration in paediatric rehabilitation, of which the aims and objectives are highlighted in the following paragraphs.

A first orientation showed that there is a considerable body of literature available on team collaboration in paediatric rehabilitation: theoretical principles and models of team collaboration are extensively described. Nevertheless, although everybody supposedly knows what collaboration means and should be well informed on the various approaches (multi-, inter- and transdisciplinary collaboration) on hand, it still proved remarkably difficult to come up with a clear definition of collaboration and to provide a complete overview of related factors and variables. In view of this and to help us define the concept of team collaboration, we first conducted a systematic review of the literature describing the elements defining team collaboration processes in paediatric rehabilitation. Subsequently, we used the most salient elements in our subsequent description and evaluation of current organizational characteristics and collaborative practices in five Dutch paediatric rehabilitation settings.
The threefold aim of this thesis hence was:
1. To define the concept of team collaboration in paediatric rehabilitation;
2. To describe the organizational characteristics of collaborative efforts in five Dutch paediatric settings and
3. To describe current collaborative practices in the care for children with cerebral palsy (CP).

1.3 Outline of the Thesis

The outline of this thesis follows the three aims of the ProCP study as described above. In Chapter 2 an account is given of the systematic review of the most salient elements defining team collaboration in paediatric rehabilitation. The survey yielded 29 elements describing six key features of team collaboration: communication, decision making, goal setting, organization, team process and parent involvement. The elements and their relevance to team collaboration are summarized and relevant elements subsequently served as guidelines in our further explorations.

Chapter 3 comprises our study of the current views on how team collaboration should be organised and we analyse the current policies and the actual involvement of the team members, which also includes the parents, in five Dutch paediatric rehabilitation settings delivering treatment to children with CP.

In Chapters 4, 6 and 7 the current practices in the five participating Dutch rehabilitation venues are described. In Chapter 4 the focus is on the family-centredness of care. We evaluate how parents perceive the family-centredness of the services they receive and how the professionals interpret their family-centred behaviours during service delivery. In a family-specific analysis we assess parental perceptions by means of the Measure of Processes of Care (MPOC) and those of the professional team members by means of the family-specific Measure of Processes of Care for Service Providers (MPOC-SP). We also analyse whether the parents’ and professional team members’ views on the importance of specific family-centred behaviour concurred and whether the parents received the care they deemed important.

In Chapters 6 and 7 the goal-setting process is the focus of study. We respectively examine the quality and content of the children’s needs, principal problems and goals as they are formulated in the centres’ treatment plans (Children’s RAPs) and whether the needs and problems are effectively integrated into the treatment goal(s).

Chapter 5 describes the utility and validity of the MPOC-SP as a family-specific measure, i.e., as filled in for each child and its family. This broadly focused, valid, and reliable instrument allows service professionals to self-assess the family-centredness of the services they deliver. In contrast to the general MPOC-SP, the family-specific version can be used for the evaluation of the care provided for each individual child and its family and may subsequently also serve as a quality-control system to help maintain or augment the family specificity of the ongoing programme.

The thesis concludes with a general discussion of the reported findings. Clinical implications are considered and recommendations for improvements of team collaboration in paediatric rehabilitation in the Netherlands are provided.
1.4 REFERENCES


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