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FAMILY-CENTREDNESS IN SERVICES AND REHABILITATION PLANNING FOR CHILDREN AND YOUTH WITH CEREBRAL PALSY IN FINLAND

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*Att våga är att förlora
fotfästet en liten stund.
Att inte våga är att
förlora sig själv.*

Søren Kierkegaard (1813-1855)

ABSTRACT

Objectives: The overall aim of this thesis was to explore and describe the family-centredness and rehabilitation planning procedure for children and youth with cerebral palsy (CP) in Finland. The main focus was on how professionals working with children and youth with cerebral palsy describe and document the rehabilitation planning procedure and how family-centredness was perceived by professionals and parents.

Methods: Participants were team members in neuropaediatric multidisciplinary teams in central and university hospitals and government special schools as well as physiotherapy private practitioners who had an agreement with the Social Insurance Institution. Parents visiting two university hospital neuropaediatric wards participated in one study (II). Family-centredness in services (FCS) was evaluated by the Measure of Processes of Care questionnaires. To get a deeper insight in the rehabilitation planning procedure, focus group interviews were conducted. Two researchers conducted the interviews which were tape recorded and transcribed. Three content areas guided the interviews: goal-setting, different transition phases and the use of the International Classification of Functioning, Disability and Health, Children and Youth version. A retrospective cross-sectional register study was used to analyze the interrelation between needs and functional difficulties and the therapeutic goals in written rehabilitation plans. The ICF-CY was used as a reference in the analysis.

Results: Professionals and parents rated the family-centred service as fair to moderate. There was a significant difference in how professionals of different disciplines rated their FCS delivery. Professionals with more than 25 years of work experience in the field of rehabilitation for children and youth with CP rated their service higher than those with shorter work experience. Parents and professionals identified common aspects in need of development, i.e. letting the family choose when and what kind of information is provided as well as providing opportunities for the whole family to obtain information. Goal setting and ways to involve families in the rehabilitation planning procedure was experienced as challenging. Collaboration with all involved in the child's rehabilitation was partly scanty and the results indicate a lack of routines in the transition phases. In the written rehabilitation plans the goals were not well reflected in the children's needs and functional difficulties.

Conclusion: This thesis identified examples in the rehabilitation planning procedure of good practice in which collaboration with various parties and clear formal processes occurred. Areas in need of development were also identified. Standardized formal programme processes and policies and a named care manager for all families could provide a starting point in developing and improving the services to ensure all families have the possibility to be involved in their child's rehabilitation service.

Key words: Family-centred service, rehabilitation planning, goal-setting, transition, cerebral palsy

SAMMANFATTNING PÅ SVENSKA

Syfte: Det generella syftet med avhandlingen var att undersöka och beskriva familjecentrering och proceduren kring planering av habilitering för barn och ungdomar med cerebral pares (CP) i Finland.

Metod: Medlemmar i neuropediatrika mångprofessionella team på centralsjukhus, universitetssjukhus och statliga specialskolor deltog i studien. Utöver dessa deltog privatpraktiserande fysioterapeuter som hade avtal med Folkpensionsanstalten (studie I) samt föräldrar till barn som besökt två universitetssjukhus neuropediatrika avdelningar (studie II). Graden av uppskattad familjecentrerad service undersöktes med hjälp av självvärderingsfrågeformuläret "Measure of Processes of Care". För att få en djupare insikt i proceduren kring planering av habilitering utfördes fokusgruppintervjuer. Två forskare deltog i intervjuerna som bandades och transkriberades. Intervjuerna fokuserade på tre områden: måluppställning, olika övergångsskeden (ss.dagis- och skolstart), samt användningen av den Internationella klassifikationen av funktionstillstånd, funktionshinder och hälsa, versionen för barn och ungdom (ICF-CY). För att analysera barnets behov och funktionella svårigheter i relation till uppställda mål utfördes en retrospektiv tvärsnitts- registerstudie av skriftligt dokumenterade habiliteringsplaner. ICF-CY användes som referens i analysen.

Resultat: Både professionella och föräldrar skattade den familjecentrerade servicen till att vara rimlig till måttlig. Bland de professionella hade olika yrken en signifikant inverkan på hur de skattade familjecentrerad service. Även professionella med över 25 års arbetserfarenhet inom habiliteringsområdet för barn och ungdomar med CP skattade signifikant högre än de med kortare arbetserfarenhet. Föräldrar och professionella identifierade samma aspekter vad gäller områden inom familjecentreringen som borde utvecklas. Identifierade aspekter var bl.a. att låta familjen välja hurdan information som ges och när den ges samt att erbjuda möjligheter för hela familjen att få information. Målsättning och olika sätt att involvera familjerna var sådant som upplevdes utmanande i proceduren kring planering av habiliteringen. Samarbete med alla involverade i barnets habilitering var delvis knapp och resultaten i avhandlingen tyder på en brist i rutinerna kring barnets övergångsskeden. I de skriftliga habiliteringsplanerna var beskrivningen på barnets funktionella svårigheter och de uppställda målen inte i relation till varandra.

Sammanfattning: Avhandlingen identifierade aspekter i planeringen av habilitering som kan anses vara god praxis med samarbete med alla involverade och klara processer och procedurer. Även områden i behov av utveckling identifierades. Standardiserade processer och handlingsplaner och en utsedd koordinator kunde fungera som en startpunkt i utvecklingen av servicen, och på så sätt försäkra att alla familjer har möjlighet att på lika villkor vara involverade i planeringen av barnets habilitering.

Nyckelord: familjecentrerad service, planering av habilitering, måluppställning, övergångsskeden, cerebral pares

TIIVISTELMÄ

Tavoitteet: Tämän väitöskirjan kokonaistavoite oli tutkia ja kuvata CP-vammaisten lasten ja nuorten kuntoutussuunnittelun prosessia ja palvelun perhekeskeisyyttä Suomessa. Päähuomio oli siinä tavassa, miten CP-vammaisten lasten ja nuorten parissa työskentelevät ammattilaiset kuvaavat ja dokumentoivat kuntoutuksen suunnitteluprosessia ja miten ammattilaiset ja vanhemmat näkevät perhekeskeisyyden toteutumisen.

Menetelmät: Tutkimus oli osa Kelan Vake -hanketta, johon osallistui moniammatillisten kuntoutusryhmien jäseniä keskus- ja yliopistollisten sairaaloiden lastenneurologisilta osastoilta sekä kolmesta valtion liikuntavammaisten lasten erityiskoulusta. Lisäksi tutkimukseen osallistui Kelan sopimussuhteisia fysioterapian avopalvelun tuottajia (osatutkimus I) sekä lasten ja nuorten vanhempia Helsingin ja Turun yliopistollisten sairaaloiden mittarihankkeesta (osatutkimus II). Kuntoutusprosessin perhekeskeisyyden todentumista palveluissa arvioitiin Measure of Processes of Care -kyselylomakkeilla. Lisäksi kuntoutussuunnitelmaprosessin teemoja syvennettiin kahden tutkijan yhdessä toteuttamalla fokusryhmähaastatteluilta, jotka nauhoitettiin ja litteroitiin. Litteroitu teksti analysoitiin sisällönanalyysillä. Lasten kirjalliset kuntoutussuunnitelmat analysoitiin systemaattisesti käyttäen Maailman terveysjärjestön toimintakyvyn, toiminnanrajoitteiden ja terveyden kansainvälisen luokituksen, lasten ja nuorten version (ICF-CY) viitekehystä.

Tulokset: Sekä ammattilaiset että vanhemmat arvioivat palvelun perhekeskeisyyden toteutuvan melko hyvin. Eri ammattiryhmien välillä oli kuitenkin merkittäviä eroja sen suhteen, miten he arvioivat palvelunsa perhekeskeisyyttä. Myös työkokemuksen pituus vaikutti arviointiin. Ammattilaiset, joilla oli yli 25 vuoden työkokemus CP-lasten ja -nuorten kuntoutuksesta, arvioivat antavansa merkittävästi perhekeskeisempää palvelua kuin lyhyemmän työkokemuksen omaavat. Näkemykset perhekeskeisyyden kehittämistarpeista olivat niin perheiden kuin ammattilaisten näkökulmasta yhtenevät. Perheiden tulisi saada vaikuttaa enemmän siihen, milloin ja millaista tietoa heille tarjotaan ja tietoa olisi jaettava nykyistä laajemmin koko perheelle. Ammattilaisten näkökulmasta haastavimmaksi koettiin kuntoutuksen tavoitteenasettelu sekä perheiden osallistaminen. Yhteistyö eri tahojen kanssa oli osittain puutteellista, ja tulokset viittaavat epäsystemaattisiin rutiineihin siirtymävaiheiden, kuten päiväkotiin ja kouluun, suunnittelussa. Kirjallisten kuntoutussuunnitelmien tavoitteet eivät heijastaneet johdonmukaisesti lasten tarpeita ja toiminnallisia vaikeuksia.

Johtopäätökset: Väitöskirjassa identifioitiin kuntoutuksen suunnittelun hyviä käytäntöjä, joita luonnehtii toimiva yhteistyö eri tahojen kanssa sekä selkeä työvaiheiden kuvaus. Myös kehittämistä vaativia osa-alueita tunnistettiin. Standardisoidut toimintaprosessit ja nimetyt perhekohtaiset koordinaattorit voisivat luoda hyvän lähtökohdan toiminnan kehittämiseksi, jotta kaikilla perheillä olisi mahdollisuus olla täysipainoisesti mukana lastensa kuntoutussuunnitelman laatimisessa.

Avainsanat: perhekeskeinen palvelu, kuntoutussuunnitelma, tavoitteiden asettelu, siirtymävaiheet, cerebral palsy

LIST OF PUBLICATIONS

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LIST OF ABBREVIATIONS

COPM	Canadian Occupational Performance Measure
CP	Cerebral Palsy
FCS	Family-Centred Service
GAS	Goal Attainment Scale
GMFCS	Gross Motor Function Classification System
GMFM	Gross Motor Function Measure
ICD-10	International Classification of Diseases, tenth version
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health, version for Children and Youth
IHDP	Infant Health and Development Program
IHAIP	Infant Behavior Assessment and Intervention Program
MACS	Manual Ability Classification System
MPOC	Measure of Processes of Care
MPOC-SP	Measure of Processes of Care for Service Providers
NDT	Neurodevelopmental Treatment
SII(F)	The Social Insurance Institution (of Finland)
WHO	World Health Organization

DEFINITIONS

- Rehabilitation** “A process aimed at enabling people to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination.” (WHO, 2011).
- Family** The child’s parents, siblings or other close relatives who belong to the child’s everyday life (Bronfenbrenner, 1989).
- Family-centred service** “Family-centred service (FCS) is made up of a set of values, attitudes and approaches for children with special needs and their families. Family-centred services recognize that each family is unique, the family is the constant of the child’s life; and family members are the experts on the child’s abilities and needs. In family-centred service the family works with service providers to make informed decisions about the services and supports the child and family receive. In family-centred service the strengths and needs of all family members are considered.” (King et al., 2004; *CanChild* Centre for Childhood Disability Research, McMaster University, 2012).
- Multidisciplinary team** Composed of several professionals representing specialized disciplines and knowledge who are working within the boundaries of their professions. Work is evolved to meet the demands of societal, environmental and real life problems that cannot be solved by single disciplines alone (Choi and Pak, 2006).

1 INTRODUCTION

Children with disabilities often require life-long rehabilitation, starting in infancy within pediatric rehabilitation and continuing into adult health care. If the children have complex disabilities, the rehabilitation frequently involves actions from many different professionals. Such specialized health care aims to improve or maintain function as well as pave the way for social participation (King, 2002; WHO, ICF, 2001; Kettunen et al., 2009). In Finland, laws and directives require that, before starting or getting the rehabilitation financed, a rehabilitation plan should be established. The rehabilitation must be planned by a multidisciplinary team that works within the public sector (Rissanen, 2008; The Social Insurance Institution, 2012). Rehabilitation for children and youth with disabilities is arranged by several stakeholders and is based on co-operation between the family and several professionals and organizations providing the service needed (Autti-Rämö, 2008). Rehabilitation is comprehensive and multifaceted (Kettunen et al., 2009), and the service provision can be challenging.

Traditionally, rehabilitation was medically focused, but during recent decades there has been a shift from a medical (paternalistic) approach to a more family-centred mode of service delivery (Bamm and Rosenbaum, 2008; Kelly et al., 2012). The theoretical base for family-centred care is the ecological system theory, which describes humans in different systems starting from the family all the way to society. The family is seen to be dependent on several systems in their everyday life (Bronfenbrenner, 1979).

This thesis was conducted as part of a national comprehensive research project on the “Evidence-based rehabilitation for severely disabled” organized and financed by the Social Insurance Institution of Finland (SIIF). The studies in this thesis were focused on rehabilitation for children and youth with cerebral palsy (CP). Cerebral palsy is a heterogeneous disorder and rehabilitation services are often multifaceted. The Social Insurance Institution (SII) is the main financier of the rehabilitation for children and youth with CP in Finland, and according to Finnish legislation the SII finances rehabilitation for persons with severe disabilities.

2 THEORETICAL BACKGROUND

2.1 FAMILY-CENTRED SERVICE

During the last few decades, health-care services have developed tremendously in line with the development of society as a whole. A paradigm shift from a traditionally medical approach to a more client or family-centred approach has occurred (Shields et al., 2003; Carlhed, 2007). Family-centred service (FCS) is today widely known as an approach which strives to engage the family as equal partners in the rehabilitation services (Rosenbaum et al., 1998; Law et al., 2003; Strock-Lynskey and Keller, 2006; Buran et al., 2009). A family-centred service approach proceeds from the assumption that there should be a balance between the professionals and the family (Corlett and Twycross, 2006) and that the parents are experts on their child's needs (Dunn, 2000; King et al., 2004). In the literature there are several definitions of FCS and depending on the purpose the definitions are age or diagnostic-specific, but FCS can also be defined in a more comprehensive way (Bamm and Rosenbaum, 2008). In this thesis the definition of King and co-workers (2004) and *CanChild*, Centre for Childhood Disability Research (2012) was used, where values and attitudes in the rehabilitation process should be positive towards the fact that each family is unique, and the strengths and needs of each family member should be taken into consideration in each phase of the process. For a child, the family is the basis in their everyday life. The family members are the child's educators, supporters and protectors (Dunst et al., 2002). The child's functioning and active participation starts in relation to the family, by playing with and observing family members (Gallimore et al., 1989). Parents, on the other hand, facilitate by their care-giving the child's development to independence (Camden et al., 2012). However, for a child with functional limitations and possible long-term dependence in the family, the situation might be completely different (King et al., 1999), and parents have expressed a high level of stress (Lach et al., 2009; Majnemer, 2012).

Rehabilitation for children and youth with cerebral palsy is planned and delivered by a diverse team of experts (Camden et al., 2012). It is of great importance that the professionals take the whole family into consideration in the rehabilitation service process, and that not only the child's needs but the whole family's needs are noticed. Many rehabilitation service providers have adopted the FCS approach (Buran et al., 2009), though there have been difficulties in implementing the FCS in practice (Bamm and Rosenbaum, 2008). The processes of FCS and its implementation was evaluated in several studies and from different angles (Goldbart and

Mukherjee, 2001; Law et al., 2003; Dyke et al., 2006; Raghavendra et al., 2007; Buran et al., 2009). An often used tool for measuring the processes of care is a questionnaire (Measures of Processes of Care). It was developed based on factors in the rehabilitation services which parents experienced important (King et al., 1995).

There are several theories and conceptual models guiding the FCS approach and from several different fields (Dunst, 1991; Desai, 1997; Litchfield et al., 2002; MacKean et al., 2005; Bamm and Rosenbaum, 2008). The main principles for all are: a mutual partnership between professionals and parents, wide and active collaboration between all involved, parents are seen as experts on their child, and the family is the primary source for strength and support (MacKean et al., 2005; Bamm and Rosenbaum, 2008). Furthermore, shared information among all involved and the child's active participation in his/her everyday life has evolved during recent years as an important factor in FCS.

LEVELS OF COLLABORATION BETWEEN FAMILIES AND PROFESSIONALS

The family's ability to influence and participate in the services varies depending on the professional's approach. Dunst and coworkers (1991; 2002) proposed a model for family involvement. The model consists of four different approaches for family involvement in practice: 1) professionally centred practice, 2) family-allied practice, 3) family-focused practice and 4) family-centred practice. In professionally centred practice, families are seen as care-receivers and professionals as the experts. Families follow the professionals' recommendations and are passive participants in the intervention. The professionals are responsible for the care, as parents are not seen as capable of the responsibility. The family-allied model is described as family guiding, where professionals guide families to implement interventions. Families are given a background role, and the professionals define the content of that role. In a family-focused approach, families are seen as capable of making choices but only among the options given by the professionals. Professionals also guide and give advice on family functioning and how it can be improved. Finally, in the family-centred approach families and professionals are partners on an equal basis and parents are seen as experts on their child's needs. Professionals are more coaches or consultants (Table I).

Table I. The family-oriented models by Dunst et al., 1991; 2002.

Model	Practice
Professionally centred	Professionals are the experts who determine the family's needs. Families' views or opinions are given little or no credence. Families are dependent on the professional's expertise.
Family allied	Families are agents for professionals for carrying out professionally recommended actions.
Family focused	Professionals give important options for family functioning to the families, from which they choose. Professionals provide advice, support and encouragement to families on the basis of their choices.
Family centred	The collaboration is based on equal decision making. Professionals are agents or consultants who strengthen the families' existing coping strategies.

THE ECOLOGICAL THEORY

The theoretical basis for FCS is found in the systems theory, which describes human existence in systems of different sizes from the individual and family to society as a whole. A holistic approach is typical for the systems theory; the focus should be on the whole, not on the individual or separate parts (Hårtveit and Jensen, 2012). Bronfenbrenner's ecological theory describing the child's development is a much used and cited systems theory within rehabilitation for children (Bronfenbrenner, 1979). The ecological theory is based on the assumption that child development strives for balance between the child and the system surrounding him/her (Bronfenbrenner, 1979). The child develops in close interaction with the environment. He/she lives his/her everyday life in several different contexts and the theory stresses the quality and the context of these various contexts (Bronfenbrenner, 2005). The child's development in the ecological theory is not based on the child's development itself, rather it is a question of continuous interaction between the child and his/her environment or the different systems in the model (Bronfenbrenner and Mahoney, 1975; Bronfenbrenner, 1989). Bronfenbrenner (1979; 2005) describes four (five) concentric systems in which the child develops. The microsystem is the closest environment for a child and includes the family and home, i.e. where the child experiences the first interactions. The microsystem also contains relatives, friends, neighbours and the institutions the child is related to, i.e. day-care, school and later on work (Garbarino, 1990). The theory is also called the bioecological systems theory.

Biology is seen as the base in the ecological theory, the microenvironment and the fuel for development. Within the bioecological system the individual is active in his/her own development (Bronfenbrenner, 2005). The next level is the mesosystem, which comprises the linkage and processes that take place between two or more settings in the microsystem, i.e. the mesosystem is a system of microsystems. All the environmental relationships in which the child is involved are included in the mesosystem. The next two levels are systems that only indirectly have an influence on the child and his/her development. The exosystem includes, for example, the parent's workplaces and the teacher's or therapist's home environment (Bronfenbrenner, 2005). Also rehabilitation and education for parents as well as adaptation-access-courses belong to this system. The macrosystem is the outermost cultural context in society and it consists of the overarching pattern of micro-, meso- and exosystem's characteristics (Bronfenbrenner, 1989; 2005). It includes the educational system, rehabilitation, health care and social care and all the laws included (Tonttila, 2007). Later also a chronosystem was developed. The chronosystem refers to how environmental factors change over time (Bronfenbrenner, 1989; 2005). As a child grows older the processes are not necessarily the same as they were when the child was younger.

All systems interact and an occurrence in one system is reflected in the others. In the ecological theory, the family is seen as the most valuable source of support for the child and can give important insight into the coping strategies needed (Bronfenbrenner, 1979). The family's own activity is considered an important factor in FCS. The family is seen as part of a societal context and the child develops in a sociocultural environment (Gallimore, 1993).

In an FCS approach it is important to support and empower the family in all the different ecological systems. Also professionals working with children and youth with CP belong in different ways to the various systems. The microsystem contains rehabilitation settings and the rehabilitation professionals which the child is in immediate contact with (Tonttila, 2007). In the mesosystem, on the other hand, social networks are built and for a family with a disabled child this system is important for support in caregiving (Garbarino, 1990), i.e. support by professionals. In the exosystem, quality, quantity and flexibility in the rehabilitation process are important factors for a child with a disability and his/her family (Tonttila, 2007). The professionals are part of the rehabilitation system and have to respect all the laws, directives and standards in their work. Finally, in the chronosystem professionals take part in, for example, the child's transition to day-care, school and adult health care. In this thesis, the professional's activity in all these systems is studied.

PARTICIPATION

The ecological theory as well as the family-oriented model both expresses different levels of participation. Professional participation, family participation and through family participation also the child's participation in the rehabilitation practice, as well as the child's participation in his/her everyday life at home, at kindergarten, at school or at the playground. The meaning of participation is not unequivocal and several definitions occur. A semantic analysis of the word shows that participation can mean inclusion, belonging, having mutual responsibility for something or to take part. Taking part here means taking part in a social commonality, an activity or a task i.e. at school (Gustavsson, 2004), inclusion means being included in a context (Molin, 2004). Belonging means belonging to certain social contexts and certain relations (Larsson, 2004). Participation seems to be experienced or be observed in the cross-line between the individual and the environment (Almqvist et al., 2004). Participation was also defined as involvement in a life situation reflecting the individual, the activity he/she is doing and the environment where he/she lives or acts (Palisano et al., 2011; Livingston et al., 2012). Participation has revealed special attention in the International Classification of Functioning Disability and Health, which during the last decade has become an important reference in rehabilitation settings.

2.2 THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

The International Classification of Functioning Disability and Health (ICF) belongs to the "family" of international classifications of the World Health Organization (WHO) and provides a wide range of information on health-related components of well-being and functioning (WHO, ICF, 2001). It was developed as a result of the change in paradigm from a medical point of view where people with functional limitations were classified as handicapped (consequences of a disease or trauma) to a biopsychosocial approach where the limitations are seen also as a result of the environmental barriers. Through the paradigm shift the individual is seen as a participator in the society and his/her functioning in everyday life is the starting point (Pless, 2011). The ICF version for children and youth (ICF-CY) was developed in 2007 as a response to the need for a version of the ICF which could be used for children and adolescents in

different sectors, such as the health, social and education sectors. The ICF-CY was designed to record the changes in physical, social and psychological development of children and youth during their first eighteen years of life (WHO, ICF-CY, 2007). In ICF-CY functioning is seen as part of the dynamic developmental process that is dependent on continuous interactions with the family. The interactions with family members and others support the child's ability to be engaged and participate as well as to socially interact (WHO, ICF-CY, 2007).

The purpose of ICF-CY is to describe the child's functioning, the level of severity of the limitations as well as to identify the environmental factors that influence functioning in a child's everyday life (WHO, ICF-CY, 2007; Pless and Granlund, 2011). The model is, however universal, and it can be used to describe function for all people, not only people with limitations or disabilities. It becomes a model of disability when a severity qualifier is added to indicate functional limitations or restrictions (Adolfsson, 2011) (Figure 1) It is designed to serve professionals of different disciplines and from different sectors and has been shown to serve as a common language for describing health and health-related states (Adolfsson et al., 2010; Björck-Åkesson et al., 2010; De Oliveira Andrade et al., 2011).

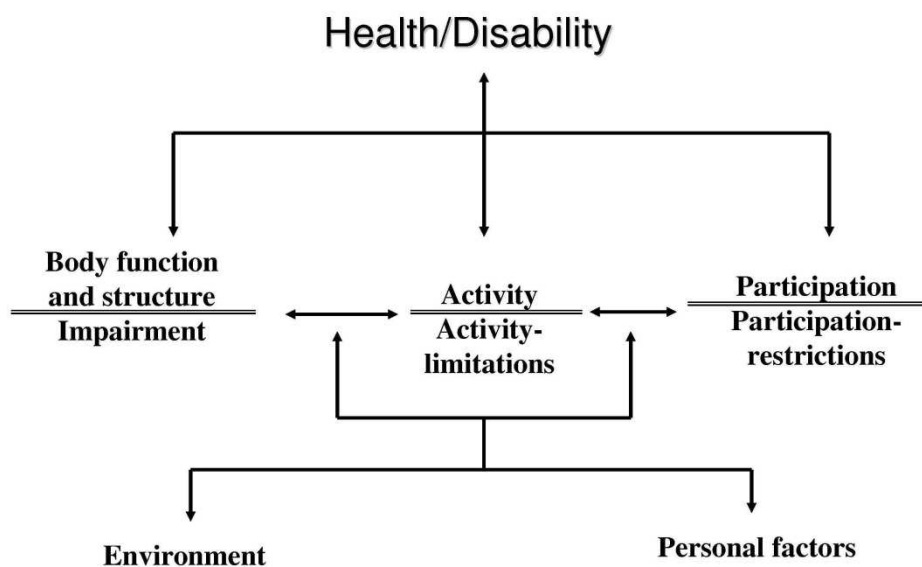


Figure 1. The conceptual model of the ICF-CY (WHO, ICF-CY 2007).

THE STRUCTURE AND USE OF ICF-CY

The ICF-CY (and ICF) can be used either as a model or as a classification. As a model ICF-CY is interactive and bidirectional. It can be used on a general level, to ensure that all the aspects of a child's functioning are taken into consideration when e.g. describing the child's needs in individual plans (Pless et al., 2011; Socialstyrelsen, 2003). Instead of seeing the child as a patient, helpseeker or client, the model facilitates professionals to see the child as a member of society with all the rights and responsibilities. The activities and participation in the child's everyday life therefore become crucial. An inability to be active or to participate can be described by both the environmental context and characteristics of the individual (Pless et al., 2011). When using the ICF-CY as a classification, functioning is classified and coded in a hierarchical structure starting with two parts (Figure 2).

The two parts of ICF-CY each consists of two components. Part one, functioning and disability, comprise the components body functions and body structures as well as activities and participation. Part two, contextual factors comprises the components environmental factors and personal factors. Each of the components can be expressed in either positive (functioning) or negative (disability) terms. Body functions are physiological and psychological functions of the body system, whereas body structures are anatomical parts of the body. Activity is defined as the execution of a task or action, and participation as involvement in a life situation (WHO, ICF, 2001; ICF-CY, 2007). Life situation is defined as activities with a personal or socially meaningful goal (Law et al., 2011). Participation has received special attention in the ICF-CY version, as the nature and settings of life situation are different for children and youth compared to adult life. As the child develops and grows also the level of participation differs (Adolfsson, 2011). When ICF-CY is used as a classification, the two dimensions of activities and participation are merged into one component (Figures 1 and 2). In the model Personal factors can be taken into consideration, whereas in the classification they are not classified due to the large social and cultural variance associated with them.

Environmental factors are defined as the complete background of the child's living and are organized in two different levels, the individual level and the societal level. The individual level consists of the child's immediate environment such as home, day-care, and school, whereas the societal level describes the social structures around the child, such as systems in the community, government agencies, and laws and regulations that indirectly have an impact on the child. Personal factors are the child's individual background, including gender, age, fitness, lifestyle coping strategies, education and personal experience (WHO, ICF-CY, 2007).

Each component in the ICF-CY consists of various domains and each domain of various categories which are the units of classification. Classification is structured and organized into chapters and domain headings under which are common categories. Each component has a letter prefix to symbolize the component (see Figure 2). The letters are followed by a numeric code starting with the chapter number and followed by numbers in the different levels (up to a fourth level). Activities and Participation are coded as one component, but can be used separately and then the prefix d is replaced by a (activity) or p (participation) (WHO, ICF-CY, 2007; Pless and Granlund, 2011).

Since its publication the ICF-CY has been used as a classification or a model (Morris et al., 2005; McDougall and Wright, 2009; Cerniauskaite et al., 2011; Maxwell et al., 2012). The ICF and ICF-CY has been criticized for not being feasible to use in clinical settings (Adolfsson, 2011). Several shortened versions of the ICF have been developed and defined to facilitate their use. The ICF checklist is a shortened version of the ICF, containing all four components in one level chapter and two level categories (WHO, 2003; Ewert et al., 2004). In addition, separate core-sets are also defined for use with certain patient groups and these include the most important categories for the particular patient group in focus (Grill et al., 2006). However, no core sets for any group of children with disabilities have been developed so far. An often used method for analyzing the presence of ICF/ICF-CY in a study are the linking rules, a standardized process used to link outcome measures and interventions to the ICF/ICF-CY (Cieza et al., 2002; Cieza et al., 2005). Beyond these application instruments of ICF and ICF-CY also different training tools and questionnaires have been developed (WHO, 2012).

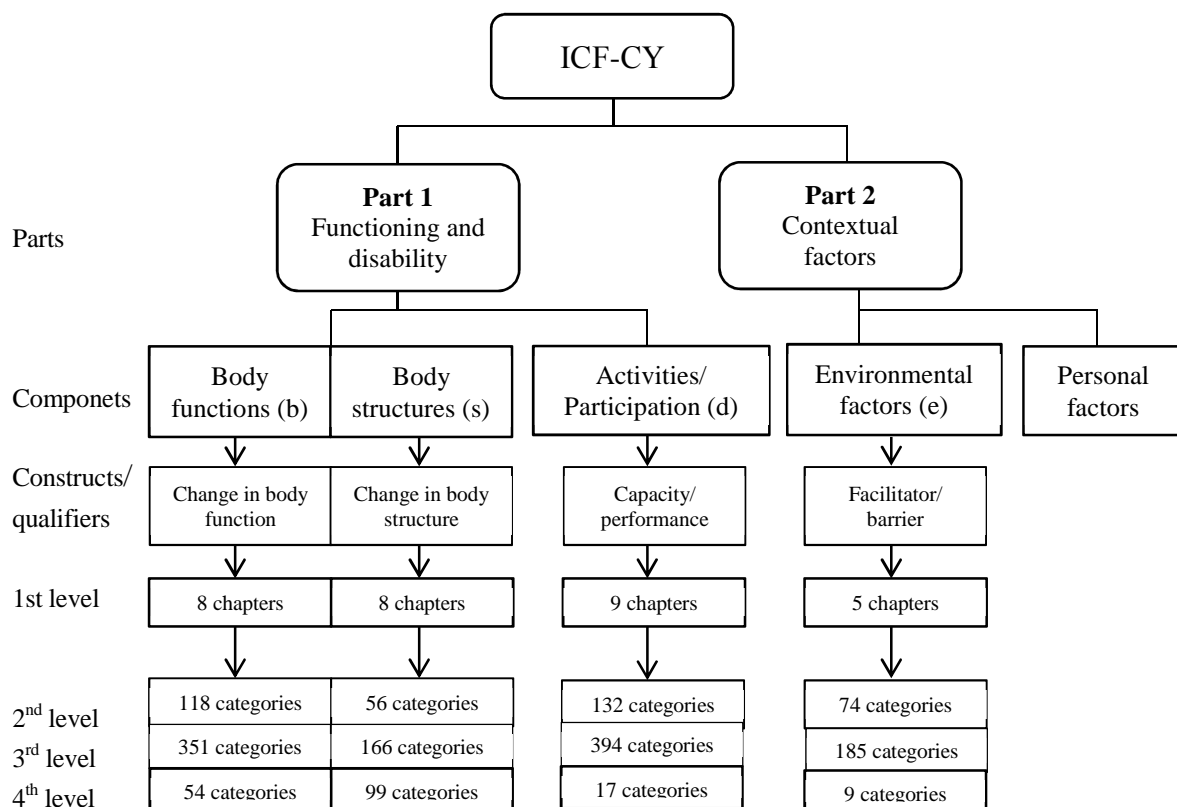


Figure 2. The structure of the ICF-CY (WHO, 2007). Adapted from Paltamaa (2008) and Adolfsson (2011).

2.3 THE MULTIDISCIPLINARY TEAM

Rehabilitation services for children and youth with disabilities require participation and sharing expertise from several different health and social care professionals (Yerbury, 1997; Rosenbaum, 2007). Finnish legislation recommends rehabilitation to be planned and followed up by a team involving multiple disciplines (Rissanen 2008; SII 2012). Best practice in health care today is working in teams, and teams are considered to provide better care and rehabilitation than professionals working in isolation (Firth-Cozens, 2000). Co-ordinated multidisciplinary team work gives several benefits for the child in rehabilitation settings and services. Improved communication between professionals and professionals and child/parents, a clear role for the family in the rehabilitation process, consensus on management, shared documentation and clear coordination have shown to be advantageous (Yerbury 1997; Choi and Pak 2007). This approach can also contribute to improving functional outcomes and reduce costs (Bent et al., 2002; WHO, 2011), and to being useful when the aim is to solve real-life or everyday-life problems (Choi and Pak 2006). Members of a well-functioning team sense less

stress, i.e. produce better services through a greater sense of participation and support (Firth-Cozens, 2001).

Multidisciplinary teamwork is, however, sometimes difficult to achieve. Such difficulties might arise from poor processes of team functioning, discipline conflicts and poor communication between professionals (Choi and Pak, 2007). Also differing knowledge and attitudes towards how to achieve good outcomes as well as hierarchical organizations, i.e. authority and unsure responsibility roles can make team working complex and might stand as a barrier (Firth-Cozens, 2001). Team working is sometimes seen as time consuming, and enough time for teamwork and development is not always available (Carter et al., 2003). Sufficient resources to allow time for good communication both with clients and within the team is needed in all team organizations (Firth-Cozens, 2001). It is important to ensure that all participants in a team know his/her role. Insecurity might lead to increased stress, a feeling of being undervalued and enhance poor staff morale. There might also be a risk for providing contradictory information or that some information will not be provided at all, if team members have an unsure idea as to what fields of knowledge their team colleagues are covering (Jenkins et al., 2001; Lemieux-Charles and McGuire, 2006).

Teams are composed of different professionals who all possess a variety of skills and knowledge to produce good care (Firth-Cozens, 2001). In the literature three types of multiple disciplinary teams are most frequently described (Stokols et al., 2008; Choi and Pak, 2006; Choi and Pak, 2008): multidisciplinary team, interdisciplinary team and transdisciplinary team. The multidisciplinary team is the most basic level of team, where multi refers to many, i.e. a team with several members (Choi and Pak, 2006). In a multidisciplinary team each professional works as an independent expert who assesses the child, sets goals, determines an intervention and evaluates the improvement separately (Wilson and Pirrie, 2000). The team members act within their own professional curricula and work independently of the others, in a way locked within their own disciplinary boundaries (Choi and Pak 2006; 2007). In a multidisciplinary team there is, however, some collaboration across professions. Team members can use skills and knowledge from the disciplines represented in their team and the team can also discuss intervention strategies and plans. A multidisciplinary team is usually led by a physician, who also has the final responsibility for the child's care. Therefore, the multidisciplinary team has been defined as a hierarchical team (Patel et al., 2008). The word multiprofessional team is used as a synonym for multidisciplinary team, especially in Europe and Canada (Patel et al., 2008). In an interdisciplinary team there is a more communicative atmosphere. All team members share the responsibility for the decisions made in collaboration (Choi and Pak, 2008). The work

in an interdisciplinary team is more like a process, where each member shares his/her expertise with the others (Patel et al., 2008). Goals are set in collaboration and then the members coordinate their input according to the goals (Choi and Pak, 2006). The process is time consuming, and time is usually reserved for information sharing and discussion (Isoherranen 2006).

Pirrie and coworkers (1998) defined the difference between multi and interdisciplinary in three dimensions: numerical, territorial and epistemological. Numeric refers to the number of members in a team. Only two professionals from different disciplines are called inter- but it becomes multi- if there are three or more professionals working together. Territories refer to the disciplinary boundaries that professionals in a multidisciplinary team have. Professionals in a multidisciplinary team usually have the same epistemological view, even if a shared understanding is not guaranteed. In an interdisciplinary team, on the other hand, the boundaries are blurred and there might be new ways of working together (Nolan, 1995; Pirrie, 1998; Choi and Pak, 2006).

Transdisciplinary team work has been defined as integrating “the natural, social and health-care sciences in a humanities context” (Soskolne, 2000; Choi and Pak, 2006; Stokols et al., 2008). In transdisciplinary work professionals change roles and start their work by looking at the child as a whole. Each professional helps the others to acquire skills that are needed (Stokols et al., 2008). Goals are set in collaboration and skills are shared (Choi and Pak, 2006). Exchanging professional skills requires trust and courage to accept that other professionals can do what they were trained to do and to accept to do work that one was not trained to do. Transdisciplinary work requires the capacity to share information and to make professional boundaries invisible (Isoherranen, 2006).

2.4 CEREBRAL PALSY

The term cerebral palsy is probably one of the most familiar disorders both for professionals in the area of health care and social services and for the “man in the street” (Morris, 2007). The cause, definition, classification, outcomes of functional impairment and best treatment however, are not necessarily clear even for the most experienced clinician. Cerebral palsy as a disorder is complex and heterogeneous and there has been a discussion of the most valid definition for decades (Bax and Brown, 2004). A need for a common international terminology, new knowledge and understanding of developmental neurobiology as well as the idea that the

treatment of persons with CP should be managed by a multidisciplinary team have led to a new definition of CP. This new definition, modified by members of an international workshop organized by an Executive committee 2006, is documented as follows:

“CP describes a group of permanent disorders of the development of movement and posture, causing activity limitation(s) that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behavior, by epilepsy and by secondary musculoskeletal problems.”
(Rosenbaum et al 2007).

Persons with CP have a large variety of symptoms and the definition is broad to cover all the different issues. Therefore, it is important to further classify or neurologically describe the type of CP (Rosenbaum et al., 2007; Krägeloh-Mann and Cans, 2009). Traditionally the classification has been based on typographical distribution of affected limb and dominant type of motor symptoms (i.e. hemiplegia, diplegia, quadriplegia, spastic, dyskinetic, ataxic) (Stanley et al., 2000; Bax and Brown, 2004). Today there is a recommendation to use a more descriptive classification that includes several components. These components are: 1) motor abnormalities, including nature and typology of the motor disorder and functional motor abilities, 2) accompanying impairments, 3) anatomical distribution and neuro-imaging findings, and 4) causation and timing (Rosenbaum et al., 2007).

CP is said to affect 2-3 children per 1 000 live births and is one of the most common causes of serious disabilities in childhood (Surveillance of Cerebral Palsy in Europe, 2000; Westbom et al., 2007; Krägeloh-Mann and Cans, 2009). The same rate is also reported to be valid in Finland (Mäenpää, 2012) and there are approximately 6000-7000 persons with CP in the country (Halonen et al., 2009). CP is an umbrella term covering consequences on motor performance from lesions or anomalies of the immature brain. The etiology is a one-time lesion, though often caused by a cascade of events (Mutch et al., 1992; Stanley et al., 2000). The maturity of the central nervous system as well as the timing, size and duration of the lesion are factors influencing the outcome. About half of the children diagnosed with CP are born preterm with low or very low birth weight (Pharoah et al., 1996; Krägeloh-Mann and Horber, 2007) and the most common lesion is seen in the periventricular white matter (Krägeloh-Mann and Cans, 2009).

CP is the most common diagnosis among children and adolescents with motor disabilities in rehabilitation services internationally (Surveillance of Cerebral Palsy in Europe, 2000) as well as in Finland (Halonen et al., 2010). It is a lifelong disorder and life expectation is about the same as for the healthy population in general (Bax and Brown, 2004; Edwards, 2004). Persons with CP need long-term rehabilitation and treatment throughout their lives. Children or youth with CP do not face challenges limited to physical impairments alone; rather the accompanying impairments also have a major impact on the functioning in everyday life. Children with CP usually receive structured and intensive rehabilitation, psychosocial and educational support and are systematically followed by health-care service (Stevenson et al., 1997). A wide spectrum of different treatments and interventions, as well as great variations in therapy frequency and intensity, are used to modify the natural course of the disorder (Bower et al., 2001). Lately, activity-focused, goal-directed therapy has shown to be effective in rehabilitation for children with CP (Ketelaar et al., 2001; Ahl et al., 2005; Löwing et al., 2009; Löwing et al., 2010; Størvold and Jahnsen, 2010; Sørtdahl et al., 2010) as well as a family-centred approach (King et al., 1999; Jansen et al., 2012). Recently Rosenbaum and Gorter (2012) calls for rehabilitation not only to focus on function, but also incorporate fitness, fun, friends and future. These multidimensional issues and concerns cannot effectively be managed by one professional alone. Therefore, multidisciplinary teamwork is highly recommended in the rehabilitation services for children and youth with CP (Rosenbaum et al., 2007; Dodd et al., 2010).

2.5 REHABILITATION SERVICES FOR CHILDREN AND YOUTH WITH CP IN FINLAND

Finland ratified the United Nation's Declaration on the rights of the child. In the declaration it is stated that it is the child's right to achieve the fullest possible social integration and individual development as well as the right to active participation in the community (article 23). It is also stated that the best interests of the child shall be of primary consideration in all situations (article 3) and there should be respect towards the parent's responsibilities, rights and duties (article 5). In Finland, rehabilitation is seen as an investment in the future (The Rehabilitation Statement 2002). It should always be goal directed and aim to prevent and maintain the ability to manage everyday life (Autti-Rämö, 2008). The main elements of rehabilitation organization

are legislation, organization and financing of rehabilitation service and the professionals working in the rehabilitation field (Paatero et al., 2008).

Municipal health care has the main responsibility for arranging medical rehabilitation. It is based on the rehabilitation legislation, which is based on the Public Health Act (605/1991), the Act on Specialized Medical Care (609/1991) and on the Act on Health Care (1326/2010). The rehabilitation law concerning the SII was renewed in 1991 with the purpose of unifying the rehabilitation organization and to ensure service for every individual with a disability, irrespective of the region the person is living in. Another purpose was to elucidate the rehabilitation services, rehabilitation financing and distribution of work between the different organizers (Autti-Rämö et al., 2011). In the renewing process the Social Insurance Institution was assigned statutory liability to provide so-called demanding medical rehabilitations for persons with severe disabilities (610/1991, 566/2005). Severe disability in the law is defined as as “a person whose medical and functional limitations result in need of rehabilitation services at least for one year, who does not receive institutional care and whose functional limitation or disability results in extensive difficulties in everyday life”. Furthermore a possibility to enhance and maintain functionality through rehabilitation is required (566/2005). The medical rehabilitation for children with severe disabilities is aimed to maintain functional ability (later on also work ability) and promote autonomy for the children who have a long-lasting need for rehabilitation (the SII, 2012).

The medical rehabilitation provided by the SII is sometimes demanding from the family’s point of view as implementation of the rehabilitation presupposes co-operation between many different actors and organizations (Järvikoski et al., 2012). Eligibility for medical rehabilitation through the SII presupposes the need for rehabilitation and that children under 16 years of age have in addition been granted disability allowance at the middle or highest rate. The middle rate is provided for children whose need for care is demanding on a daily basis and for the highest rate where committed round-the-clock care is needed. With increasing age the need for rehabilitation and daily care often reduces, which in turn leads to a situation where the responsibility for organizing the rehabilitation is transferred to the municipality. In addition, if the organization responsibility is unclear (i.e. vagueness of the person's level of disability) the municipality has the ultimate responsibility (Health Care Act 2011).

In all the rehabilitation laws and directives it is pointed out that the client is in focus and that all rehabilitation should start from the client’s needs. To enhance the rehabilitation path for the

individual there is a law concerning rehabilitation collaboration (497/2003; Paatero et al., 2008). According to this law there should be a collaboration between professionals and organizations at the local level (a spokesman from the education service, social welfare, the Social Insurance Institution and public health), the regional level (hospital district) and the national level (advisory board named by the government) (Kettunen et al., 2009). Children usually have several plans, like an educational plan, a social service plan and a rehabilitation plan, with goals according to the child's situation. The different services should form a whole which should be presented in a comprehensive rehabilitation plan (Kettunen et al., 2009).

THE REHABILITATION PLAN

A requirement for starting rehabilitation or getting finance for the rehabilitation is the rehabilitation plan (Rissanen, 2008; 2005/566 §9, §10). The rehabilitation plan has to be set by the public sector responsible for the child's health care. Also when the SII is the organizer and financer of the rehabilitation the plan has to be made by the public health care. The formal rehabilitation is then, however, organized by the SII. The rehabilitation plan is defined as a written document made by the physician in charge or the physician together with a multidisciplinary team (Rissanen 2008; the SII, 2012). The plan should always be made together with the client or with the client and his/her family. In general there are certain factors that should be present in a written rehabilitation plan. These are: 1) the compiler of the plan, 2) client information, 3) evaluation of the need of rehabilitation, 4) rehabilitation goals, 5) actions and steps according to the goals, 6) social services, 7) evaluation and follow-up, and 8) communication between the client and the rehabilitation professionals (Rissanen, 2008). The rehabilitation is arranged to enhance or keep up the child's functioning and ability to manage in everyday life. The SII require that the plan should contain information about the person's disease, life situation, medical or functional difficulty in daily life, rehabilitation goals and the persons commitment to the goals as well as the rehabilitation service needed (including schedule, timing, duration, sectioning) with reason and realizer. In addition, it is desirable to mention who was present when the rehabilitation plan was made (Standard for medical rehabilitation arranged by SII, version 5/1.1.2007).

The rehabilitation plan has two main purposes. First it is a document required by law. In that sense it is a document which provides information from one organization to another, i.e. a document for professionals, decision-makers and financiers (Nikkanen, 2010). On the other

hand, it is also a document in which the child's medical and functional state is documented as well as the goal and intervention plan. Thus, it is a document which facilitates the family to carry out and be engaged in their rehabilitation process (Järvikoski and Härkäpää, 2004).

Rehabilitation planning for children and youth with CP is complicated, complex and challenging. In the neuropsychiatric wards at the central and university hospitals in Finland, rehabilitation is planned by a multidisciplinary team. The rehabilitation is usually planned for 12 months, but the time period can be shorter when the child's situation is difficult to anticipate or longer when the developmental trajectories and need of rehabilitation can be forecasted (the SII, 2012). It is also important to notice that planning rehabilitation for children and youth is a multifaceted process, and several aspects have to be taken into account (Figure 3). Professionals need to accept that rehabilitation is not always realized as planned and that planning the correct most effective interventions at optimal timing for the child is not always possible (Autti-Rämö, 2008).

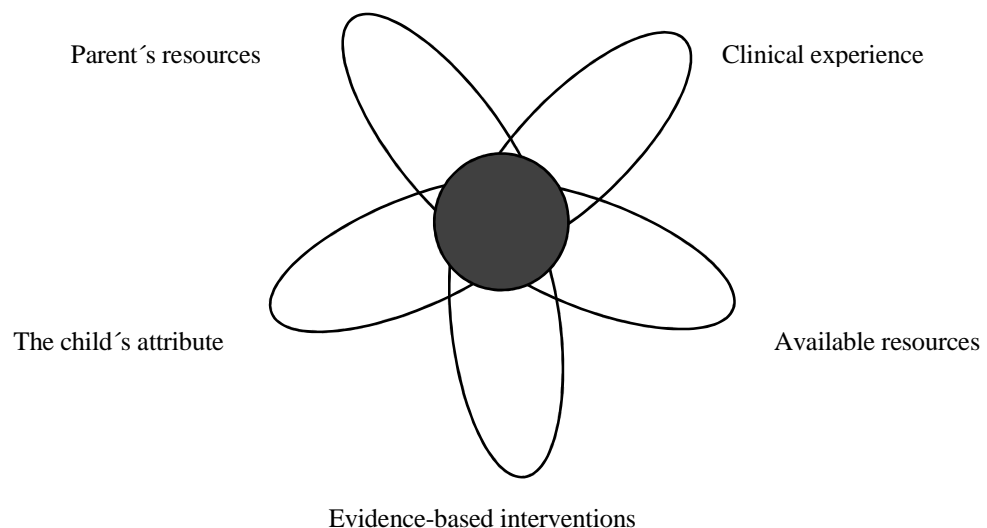


Figure 3. Factors influencing rehabilitation planning. Adapted from Autti-Rämö (2008).

GOAL SETTING

In rehabilitation planning, goal-setting is fundamental, as goals reflect the desired outcome of therapy. Goals are considered to enhance motivation and facilitate the individual to strive for the goal to be reached (Locke and Latham, 2002; Siegert and Taylor, 2004; Mastos et al., 2007; Cusick et al., 2007). Clinical observations, standardized tests, interviews and written reports from different sources are used to evaluate changes in goal-based outcomes (McDougall and

Wright, 2009). Clear and demanding goals lead to a higher level of task performance than vague and abstract goals (Locke and Latham, 2006). Accordingly, goals should be precise, explicit and well defined in order to allow evaluation of outcomes (Siegert and Taylor, 2004), as well as communicated in an understandable way for all involved in the rehabilitation process, financiers included (Schut and Stam, 1994). Goals should also be set demanding enough to enhance motivation, but easy enough to be attainable. If goals are set by the person himself/herself, are realistic and measurable this enhances self-efficacy and facilitates commitment to the goals (Locke and Latham, 2002; Åsenlöf et al., 2005).

Setting goals is a collaborative process (Siegert and Taylor, 2004) and shared goals with all involved in the decision-making process is recommended, including the family, the rehabilitation team and others participating in the rehabilitation of the child (Siegert and Taylor, 2004; Nijhuis et al., 2008a). There might, however, emerge conflicts between what the child/the family and the professionals consider as important goals (Schut and Stam, 1994; Siegert and Taylor, 2004). Maggs and coworkers (2011) found that children and parents expressed different needs, whereas Missiuna et al., (2012) found that children do not select the same goals as their parents. In the pediatric rehabilitation setting today, there is an emphasis on setting goals that are meaningful for the child and the family which focus on the child's success in completing activities, functioning and participation in everyday life (Darrah et al., 2001; Ketelaar et al., 2001; Ahl et al., 2005; Löwing et al., 2011).

Several techniques, skills and tools have been developed to support the process of goal-setting (Schut and Stam, 1994), and many advocate the SMART acronym (Specific, Measurable, Achievable, Relevant, Time-limited) as a factors to be considered when setting goals in a rehabilitation setting (Barnes and Ward, 2000). Goals are recommended to be set as long-term and short term goals, i.e. new skills or competences helping to reach a long-term goal in a reasonable amount of time (Siegert and Taylor, 2004).

3 AIMS

The overall aim of this thesis was to explore and describe the family-centredness and rehabilitation planning procedure for children and youth with cerebral palsy in Finland. The overall research question was: how do professionals working with children and youth with cerebral palsy describe and document the rehabilitation planning procedure? Special focus was placed upon identifying how family-centredness was perceived by professionals and parents.

The specific aims were:

- To explore the family-centred behaviour of professionals in multidisciplinary teams and physiotherapy service providers working with children and adolescents with cerebral palsy (Study I)
- To explore the degree to which parents experience the service provision as family-centred and to which extent the professionals in multidisciplinary teams experience their service provision as family-centred (Study II)
- To explore the service provider's experience of the rehabilitation practice for children and adolescents with CP (Study III)
- To investigate the interrelation between the child's needs and functional difficulties and the therapeutic goals as documented in written rehabilitation plans (Study IV)

4 MATERIALS AND METHODS

Over recent years, the SII has conducted and financed a comprehensive research project on the rehabilitation of persons with severe disabilities which contained systematic reviews (Jeglinsky et al., 2010; Peurala et al., 2012), evaluation of current practices (Paltamaa et al., 2009; Paltamaa et al., 2011) and perspective on children and their parents (Järvikoski et al., 2009; Järvikoski et al., 2012). Furthermore, the development of new models of interventions has been studied; of which part are currently in the analyzing phase (Karhula et al., 2012). In this thesis the focus is primarily on professionals in multidisciplinary teams taking care of children with CP.

STUDY DESIGN

The four studies were designed to encompass central aspects of rehabilitation services for children and adolescents with CP, i.e. family-centered service and rehabilitation planning. Primarily a quantitative approach was used, which was descriptive in nature. To get a deeper understanding of the rehabilitation planning procedure a qualitative approach was chosen in study III (Figure 4).

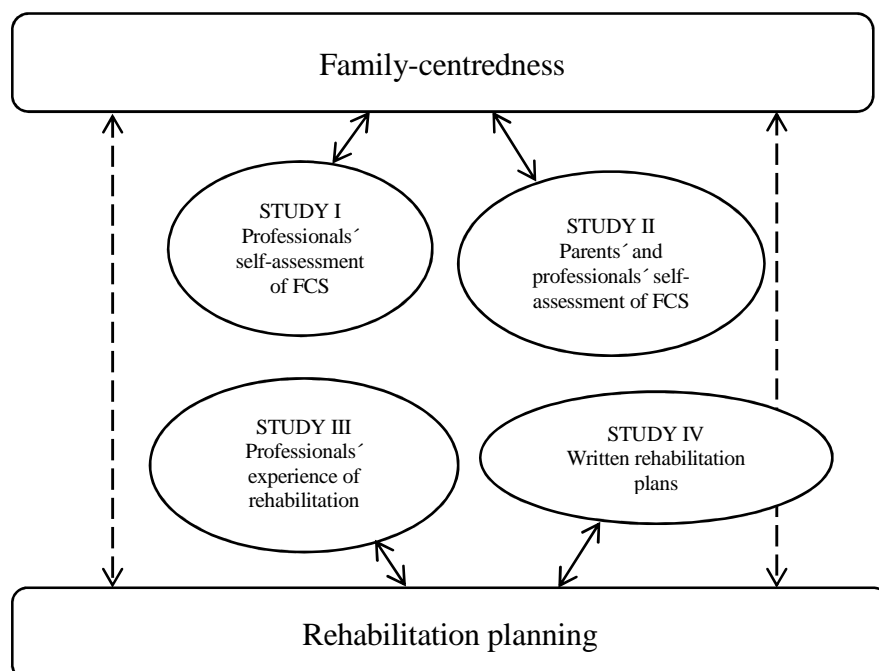


Figure 4. Methodological schema at the beginning of the four studies. FCS=Family-Centred Service

The first and second study were surveys using questionnaires, the third study was a qualitative study using focus group interviews as the data collection method. Finally the fourth study was a retrospective cross sectional study where written rehabilitation plans were used as the source of data collection (Table II).

Table II. Aims, study groups, study design and data analysis for the four studies included in the thesis. FCS=Family-Centred Service, MPOC= Measures of Process of Care, ICF-CY= International Classification of Disability and Health, Children and Youth version

Study	Aim	Study groups/ Material	Study design	Data analysis
I	Evaluation of professionals' experience of FCS	Professionals in multidisciplinary teams and physiotherapy private practitioners	Survey	Descriptive statistics, MPOC Syntaxes, Analysis of variance (ANOVA) Post-Hoc Test (Tukey)
II	Evaluation of parents' and professionals' experience of FCS	Parents of children and youth with CP Professionals in multidisciplinary teams	Survey	Descriptive statistics, MPOC Syntaxes, Analysis of variance (ANOVA)
III	Exploration of the procedures and practices in rehabilitation planning	Professionals in multidisciplinary teams	Qualitative focus group interview	Content analysis
IV	Investigation of the interrelation between needs/functional difficulties and goals as well as parental participation and multidisciplinary work using ICF-CY as a reference	Written rehabilitation plans	Retrospective cross sectional	Descriptive statistics, Kappa statistics, Analysis of variance (ANOVA)

4.1 STUDY POPULATION, MATERIAL AND PARTICIPANTS

STUDY I

The study population consisted of the neuropsychiatric multidisciplinary teams involved in the rehabilitation planning process for children and adolescents with CP in 1) all 21 central and university hospitals in Finland (n=282 team members) and 2) the three government special schools (n=45 team members) and finally 3) physiotherapy service providers/private practitioners, who informed that they had treated children with CP during 2007, who had a contract with the Social Insurance Institution during the same year and who had participated in a national survey of rehabilitation practice during 2008 (n=438). By contacting the chief senior physician at the hospitals and schools, the total number of professionals working in the teams was received (i.e. not the number per profession).

Two hospitals informed that they had not treated children and adolescents with CP during the previous year. Of the remaining hospitals all together 173 (66%) team members participated. From the government special school 28 team members participated in the survey (62%). The professionals in the multidisciplinary teams represented ten different occupations. Of the physiotherapy service providers, 124 informed that they had not treated any children or adolescents with CP during the past year, of the remaining physiotherapy service providers 311 participated (99%) (Table III).

STUDY II

Parents of children and adolescents with CP, visiting Helsinki and Turku university hospitals during April and May 2008, were invited to anonymously evaluate the FCS at the hospital's neuropsychiatric wards. During the time period a total of 67 children and adolescents with CP visited the wards. Simultaneously, professionals from the same two university hospitals' neuropsychiatric wards participated in Study I. To be able to identify strengths and weaknesses in service delivery from both parental and professional perspectives data from Study I concerning professionals at these two university hospitals was used.

A total of 53 (79%) parents completed the questionnaire (n=28 from Helsinki university hospital and n=25 from Turku university hospital). Twenty nine of the multidisciplinary team members participated at the survey (n=9 from Helsinki university hospital and n=20 from Turku university hospital) (Table III).

STUDY III

The sample in this study was purposive. Most of the children and youth with CP in Finland are treated at one of the five university hospitals. As the aim of the study was to gain a deeper understanding of the rehabilitation planning procedure, the team members in the neuropsychiatric multidisciplinary teams at the university hospitals were invited to participate in the study.

All together 45 professionals from all five university hospitals participated in the study representing nine different professions (Table III)

Table III. The participants in study I-III. The different professions and the parents are presented as numbers. Huh=Helsinki university hospital, Tuh=Turku university hospital.

Profession	STUDY I Hospital* / School	STUDY II Huh / Tuh	STUDY III
Nurse	36/3	1/4	7
Physiotherapist	24/8	2/5	8
Physician	23/2	0/2	6
Social worker/ rehabilitation guide/instructor	22/2	0/2	7
Occupational therapist	16/7	2/2	7
Speech and language therapist	15/2	1/1	5
Psychologist	14/2	1/1	4
Other **	16/2	2/3	1
PT service providers	311		
Parents		28/25	

*seven subjects did not mention their profession

**teachers, nursemaids/child care worker, administrative staff

Overlapping: The professionals from Helsinki and Turku university hospitals in Study I were included in Study II.

STUDY IV

The material in Study IV consisted of randomly chosen individual written rehabilitation plans from the register of the Social Insurance Institution for 77 children and adolescents with CP in four different age groups; 1-2 years, 5-6 years, 11-12 years and 15-16 years. There is usually some kind of transition in the lives of Finnish children in these age groups: 1-2 years the diagnosis of CP might be stated and day-care may start, 5-6 years pre-primary school starts, 11-

12 years the child transit to secondary school, 15-16 the youth transit to further education/high school and to adult health care. These age groups were chosen as it was hypothesized that the transitions would be visible in the written goals. The individual rehabilitation plan includes statements from primarily medical doctors/physicians, but also from members of multidisciplinary teams. The plans can also include, as an enclosure, statements from private practitioners/service providers working with the child in his/her home region as well as statements from the child's day-care centre/pre-primary school or school. The inclusion criteria for the rehabilitation plans were: 1) plans from children and adolescents who had an ICD-10 classification group of G80, 2) children and adolescents to whom rehabilitation had been permitted and financed through the Social Insurance Institution during 2007, and 3) documents that contained either a short-term or long-term individual rehabilitation plan (six month to three year plan).

Written rehabilitation plans from 70 children and adolescents were included in the study. The mean age was 9.1 years (SD 5.5), a few more boys than girls and most of the children were diagnosed with bilateral (n=23, 33%) or unilateral (n=22, 31%) spastic CP. Thirty one had been classified according to the GMFCS levels I-V, the rest were classified according to the GMFCS levels by the authors, based on the descriptions of functional difficulties in the individual rehabilitation plans. Manual Classification System (MACS) and Bimanual Fine Motor Function were not documented in any of the children's plans (Table IV).

Table IV. Characteristics of the children and adolescents whose individual rehabilitation plans were analyzed in study IV. Number of children in each age group, gender presented as number of girls/boys, and number of children in each ICD-10 class. Gross Motor Classification System (GMFCS) is presented as number of children in each level.

G80=cerebral palsy, G80.0=Quadriplegia, G80.1=Diplegia, G80.2=Hemiplegia, G80.3=Dyskinesia, G80.4 Ataxia, G80.8=Other CP, G80.9=Unspecified CP.

Age in years	n	Gender girls/boys	ICD-10								GMFCS				
			G80	G80.0	G80.1	G80.2	G80.3	G80.4	G80.8	G80.9	I	II	III	IV	V
1-2	16	8/8	2	0	3	7	0	0	2	2	4	5	2	2	3
5-6	18	8/10	0	1	6	9	0	1	0	1	4	8	4	0	2
11-12	18	9/9	0	1	5	5	2	1	3	1	4	5	3	1	5
15-16	18	6/12	1	2	9	1	3	1	1	0	1	5	7	2	3

4.2 DATA COLLECTION

In studies I and II, two versions of the Measure of Processes of Care (MPOC) were utilized. The professionals replied to MPOC for Service Providers (MPOC-SP) and parents (Study II) to MPOC- 20 (MPOC-20). The MPOC instruments are self-assessment questionnaires developed for families and pediatric service providers to evaluate the implementation of FCS (Woodside et al., 2001; King et al., 2004). Both instruments have shown very good internal consistency, test-retest reliability and validity in the original English versions as well as in translations (Woodside et al., 2001; King et al., 2004; Siebes et al., 2008). The MPOC-SP consists of 27 questions in four domains: 1) Showing Interpersonal Sensitivity, 2) Communicating Specific Information, 3) Providing General Information, and 4) Treating People Respectfully. The MPOC-20 consists of 20 questions in five domains: 1) Enabling and Partnership, 2) Providing Specific Information, 3) Providing General Information, 4) Coordinated and Comprehensive Care, and 5) Respectful and Supportive Care. The instruments allow comparisons to be made between parental and professional perceptions of service delivery (Woodside et al., 2001). The response rates for both instruments' scores ranged from 0-7, with options ranging from 1 (not at all) to 7 (to a great extent). Zero (0) means that the statement was not applicable. The statements or questions for the professionals were, e.g. "In the past year, to what extent did you....?" and for the parents, e.g. "To what extent do the people who work with your child....?". The questionnaires were translated into Finnish with the kind permission of the CanChild Centre for Childhood Disability Research, McMaster University. The validity of the Finnish versions to Finnish values was discussed in a multidisciplinary group of experts, and they were judged to be valid for Finnish practice.

In Study III, focus group interviews were used to gain a deeper knowledge of the rehabilitation planning procedure. A focus group is defined as a group of people with similar background and experience, who are experts on the topic of interest (Greenbaum, 1998; Krueger and Casey, 2009). The focus group provides qualitative data during a strictly planned group discussion aimed to give insight into the stated problem (Krueger and Casey, 2009). The members of a focus group interact with the interviewer and each other and do not need to agree or come to a conclusion in the discussion. The ideal size of a focus group is five to eight people, but traditionally a group can be up to 12 people (Krueger and Casey, 2009). For the researcher the goal is to understand the reality of the group members in the context studied (Holloway and Weeler, 1996). Two researchers were involved in the interviews, where one facilitated the

interviews and the other made notes and assisted. The interviews were held at the participants' work places in a calm and undisturbed environment. Three content areas guided the interviews: goal setting, different transition phases, and the use of ICF-CY.

The data in study IV was extracted from written rehabilitation plans for children and youth with CP, including all the attached files necessary for approving the actual interventions documented in the rehabilitation plans. The children's and youth's documents were randomly collected by clerks at the SII who copied, anonymized and sent the documents to the researcher

4.3 DATA ANALYSIS

A variety of methods were used to analyze the data in the four studies (Table II).

QUANTITATIVE ANALYSIS

Data was analyzed using the Statistical Package for the Social Sciences, version 19 (SPSS-19; IBM SPSS Inc. Chicago, IL, USA). Descriptive statistics and frequencies were used to derive background and demographic data (mean, standard deviation, range, 95% confidence interval). The level of significance was set as 0.05.

In Study I and II, the questionnaires were analyzed according to the scoring rules and syntaxes described by CanChild (Woodside et al., 2001; King et al., 2004). The differences between the means of the domains in the questionnaires as well as between the respondents characteristics (Study I) were analyzed by one-way Anova. In Study I, Post-Hoc (Tukey) was used for the in-depth analysis.

In study IV, the Cohen's Kappa coefficient was used to analyze the agreement between two raters. Kappa coefficient allows analyses of agreement by chance, by counting the proposition of cases that the raters agree minus the proposition of cases they are likely to agree by chance (Cohen, 1968; Machin et al., 2007). The content of rehabilitation in relation to the child's age and level of severity was analyzed by analysis of variance (Anova). The texts in the rehabilitation plans were coded according to the ICF-CY, using the linking rules described by Cieza et al. (2002; 2005) and the ICF Checklist as references. The texts including the goals in the plans were linked to the most precise codes on 1st or 2nd and when needed 3rd level. The needs and functional difficulties were considered reflected in the goals when the ICF-CY code

for a need or functional difficulty fell in the same category as the ICF-CY code for the goal. Information that was not able to link to a specific ICF-CY code was assigned not-definable (nd) with an abbreviation not definable - development (nd-dv) for items covering child development in general (Cieza et al., 2005; Fayed et al., 2012). Therefore categories coded as not definable were considered as matches only if the same not definable code was found in the needs/functional difficulties and the goal.

QUALITATIVE ANALYSIS

The qualitative approach in study IV was not guided by any of the traditional qualitative methodologies, and the methodology used was therefore classified as a generic qualitative research (Caelli et al., 2003). The focus of the study was to understand the rehabilitation planning procedure, i.e. the experience of the multidisciplinary team and the aim was to describe the phenomena. It is, however, important to explain the epistemological position from which the research was begun, in particular if the research has a generic approach. To strive for credibility the study addressed the following issues (based on Caelli et al., 2003). 1) The theoretical positioning was determined, i.e. what led to the research question, what were the researcher's motivation and disciplinary affiliation leading to the question. This study was led by earlier identification of large differences in the content of medical care and rehabilitation of children with CP in Finland (Autti-Rämö et al., 2007). 2) To distinguish between methodology and methods, in this study we used focus group analysis as a method to collect the data. 3) To describe the strategies to establish rigor. Special effort was taken throughout the study to enhance rigor by reporting the process and choices in relation to the research questions. 4) To examine the data through an analytic lens, i.e. every aspect of the study was guided by the underlying assumptions of the approach (epistemology and ontology). Furthermore, the research questions were based on the theoretical context, the results of the interviews were analysed in the light of the theory, which in turn were used to obtain the themes.

The interviews were analyzed by qualitative content analysis described by Graneheim and Lundman (2004). Manifest, latent and conventional content analyses were used (Graneheim and Lundman, 2004; Hsieh and Shannon, 2005). Credibility was increased by regular meetings held by the research team to confirm the coding and to discuss the interpretation of the analysis. As the research team was multidisciplinary (physiotherapist, occupational therapist and paediatric neurologist), the research problem and the data could be viewed from different angles. Transferability, i.e. whether knowledge obtained from this study can be transferred to another similar context, was paid attention to by purposive sampling. The participants had an in-depth

knowledge of the phenomena under study, the context was the university hospital neuropsychiatric ward and they represented multidisciplinary teams.

4.4 ETHICAL CONSIDERATIONS

In accordance with the ethical guidelines stated in the Helsinki declaration, generally accepted scientific principles were followed, the design and performance of each study was clearly described and the results were objectively and explicitly reported. None of the studies involved risks for the participants and participation was voluntary. The subjects were all informed of the right to refuse to participate or to withdraw their consent to participate at any time without reprisal.

Studies I, II, III and IV received ethical approval from the Ethical Committee at the Social Insurance Institution (3/2008, 4/2008). Study II received ethical approval concerning the parental participation by the university hospitals in Helsinki and Turku (420/13/03/03/2008). In Study I and II, the participants were informed about the study and participation by an information letter. Questionnaires were sent to the professionals by assistants at the SII and returned anonymously to the researchers. Parental participants were informed by word of mouth and in writing and were told that participation was voluntary. As only the ratings of FCS were asked about and no background variables, no informed consent was obtained from the families. The questionnaires were returned anonymously. In Study III, the professionals who agreed to participate were given written information ahead of the interview and verbal information was given before starting the interviews. As the questions asked were about their experience and no questions about the children they treated, no informed consent was obtained. In Study IV, the written rehabilitation plans were made anonymous and were assigned codes. The data was collected, reported, stored and handled during the process so that the identities of the participants would not be disclosed.

5 RESULTS

The findings from the four studies are presented according to the overall research question and the special focus, i.e. how professionals working with children and youth with cerebral palsy describe and document the rehabilitation planning procedure with special focus on identifying how family-centredness was perceived by professionals and parents.

5.1 FAMILY-CENTRED SERVICE

The professionals in both the multidisciplinary teams as well as the physiotherapy private practitioners self-rated their family-centred behaviour as fair to moderate. The domain “Treating People Respectfully” was rated highest and the domain “Providing General Information” the lowest (Table V).

Table V. Numbers, mean, standard deviations and ANOVA for the four domains of MPOC-SP for the multidisciplinary team members at the hospitals (n=282) and governmental special schools (n=28) and for the physiotherapy service providers (n=311).

Overlapping: The professionals from Helsinki and Turku university hospitals in Study I were included in Study II and are therefore part of the team members in this table.

	Showing Interpersonal Sensitivity	Providing General Information	Communicating Specific Information	Treating People Respectfully
	n Mean (SD)	n Mean (SD)	n Mean (SD)	n Mean (SD)
Hospital multidisciplinary team members	166 5.24 (0.81)	123 4.47 (1.12)	158 5.15 (1.22)	169 5.56 (0.67)
Governmental special school multidisciplinary team members	25 5.07 (0.53)	21 4.55 (1.13)	25 5.17 (0.90)	27 5.57 (0.68)
Physiotherapy service providers (local therapists)	276 5.05 (0.92)	275 3.72 (1.31)	289 4.92 (1.24)	292 5.65 (0.70)
F-value (d.f.=2,415)	2.910	17.649	1.875	1.120
P-value	0.055	0.00*	0.154	0.327

*P<0.05

There were statistically significant differences in how professionals in the multidisciplinary teams self-rated their family-centredness in the following domains: “Showing Interpersonal Sensitivity” ($p=0.04$, $F=2.12$), “Providing General Information” ($p=0.01$, $F=2.64$) and “Communicating Specific Information” ($p=0.00$, $F=9.85$). “Providing General Information was rated highest by social workers and rehabilitation guides with significantly higher rates than nurses ($p=0.02$), occupational therapists ($p=0.01$) and psychologists ($p=0.04$). Nurses rated their FCS significantly lower than the physiotherapists ($p=0.00$), occupational therapists ($p=0.00$), speech and language therapists ($p=0.00$), physicians ($p=0.00$) and psychologists ($p=0.00$) in the domain “Communicating Specific Information”.

WORK EXPERIENCE AND FCS

Work experience in the field of rehabilitation for children and youth with CP had an impact on how the professionals self-rated their FCS. When comparing the means of the multidisciplinary team members' ratings in relation to work experience, there was a statistically significant difference in the domain “Providing General Information” ($p=0.01$). Team members with more than 25 years of work experience in the field of rehabilitation for children and youth with CP rated significantly higher values than those with 0-5 years ($p=0.02$), 6-10 years ($p=0.00$), 11-15 years ($p=0.04$) and 16-20 years ($p=0.04$) of work experience. The mean of the physiotherapy service provider's ratings in relation to work experience showed statistically significant differences in the three domains “Showing Interpersonal Sensitivity” ($p=0.00$), “Communicating Specific Information” ($p=0.03$) and “Providing General Information” ($p=0.00$). The service providers with more than 25 years of work experience rated statistically significantly higher in the domain “Showing Interpersonal Sensitivity” than those with 0-5 years of work experience ($p=0.01$), in the domain “Communicating Specific Information” than those with 6-10 years of work experience ($p=0.02$) and in the domain “Providing General Information” than those with 0-5 years ($p=0.01$) and 11-15 years of work experience ($p=0.05$).

PARENTS RATINGS OF DELIVERED FCS

To localize weaknesses in service delivery, items for which 33% or more of the respondents scored a behaviour occurring between 1 and 4 (“not at all” to “to a moderate extent”) on the MPOC's seven-point scale was analyzed. The professionals rated items within three of the four domains: “Showing Interpersonal Sensitivity” (2 items), “Providing Specific Information” (2

items) and Providing General Information” (5 items). All the items in the domain “Providing General Information” were areas in which at least 33% of the professionals responded as occurring sometimes or less.

In Study II, parents from two university hospitals had the possibility to evaluate the family-centred processes of care at the hospital’s neuropsychiatric wards. All together 53 parents/caregivers completed the MPOC-20 questionnaire. As the parents were few and there were no statistically significant differences between parents in the two university hospitals (enabling and partnership $p=0.28$; providing general information $p=0.12$; providing specific information $p=0.24$; co-ordinated and comprehensive care $p=0.21$; respectful and supportive care $p=0.34$) the data were merged. Parent’s results are thus reported as one group. Generally parents rated the service as fair to moderate. The domains “Respectful and Supportive Care” ($M=5.54$, $SD=0.96$) and “Coordinated and Comprehensive Care” ($M=5.48$, $SD=1.02$) were rated highest. Lowest was the domain “Providing General Information” ($M=4.34$, $SD=1.17$) (Table VI).

Table VI. Number, mean and standard deviation for parents (n=53).

Domain	N (%)	Mean (SD)
<i>Parents / caregivers</i>		
Enabling and Partnership	53 (100)	5.26 (0.94)
Providing General Information	51 (96)	4.34 (1.17)
Providing Specific Information	52 (98)	5.17 (1.22)
Coordinated and Comprehensive Care	50 (94)	5.48 (1.02)
Respectful and Supportive Care	51 (96)	5.54 (0.96)

Parents located weaknesses in the FCS in three of the five domains: “Providing Specific Information” (1 item), “Enabling and Partnership” (1 item) and “Providing General Information” (5 items). Both parents and professionals rated weak the items providing written information of what the child is doing in therapy, having written information available about the child’s disability and providing information on how to get in contact with other parents. Both parents and professionals also identified as a weakness that it was not possible to get/give information in a manner and at a time that was suitable for or according to the needs of the

parents and in a way that the whole family could obtain similar information. Parents also experienced that there was a lack of information about services offered in the local community as well as information in the form of DVDs, booklets, etc.

THE MULTIDISCIPLINARY TEAM'S EXPERIENCE OF FCS

There seemed to be no systematic practice in how to involve parents in the rehabilitation planning process (Study III). Multidisciplinary team members in the university hospitals experienced that involving parents was demanding and they were unsure of the role of the parents in the process. This finding was corroborated in the written rehabilitation plans, where the parents' or the families' presence was mentioned in only 51% of the plans (n=36/70) (study IV). Different practices occurred in the hospitals, but all had in common that the physician interviewed the family/parents at the beginning of the hospital visit. Parents were also often present when the therapists assessed the child. During the interview and assessments, parents had the possibility to discuss the day-to-day problems and needs that arose in the child's life. However, it remained unclear how the parents' needs were met (Study III). In the written documents and rehabilitation plans the parents' or the families' needs or wishes were documented only in 6% (n=4/70) (Study IV). During the different transition phases there was some collaboration with the parents. Especially when the child entered day-care, the parents were involved in collaboration with the university hospital's multidisciplinary team members. Additionally, if a child was classified as having an intellectual disorder or severe learning difficulties the transition to special care units occurred in close collaboration with the parents. During the transition process to adult health care, the family was involved in the planning stage, but after that the family usually contacted the adult health-care provider to schedule time for the first visit. The focus groups also brought up the term "learned passivity" which meant that the rehabilitation planning procedure happened mostly "above the child's head", i.e. the child was not involved or did not participate actively in matters that concerned his/her life. Consequently the child learned that others (professionals and/or parents) decide about rehabilitation and things that concern their everyday life.

5.2 REHABILITATION PLANNING

To investigate how the professionals described the rehabilitation planning procedure, 45 multidisciplinary team members from five university hospitals participated in focus group

interviews (Study III) and the rehabilitation plans for 70 children and adolescents between the age of 1-16 years were analyzed (Study IV). Three content areas guided the interviews: goal setting, the different transition phases and the use of ICF-CY. The team members in the multidisciplinary teams were experts on the topic of interest.

In Study III, three themes arose from the focus group discussions: 1) challenging goal setting, 2) transition without routines, and 3) ICF-CY not in use. The themes were based on four sub-categories: a) dilemma of parents' role, b) co-operation, c) care of children with intellectual disorders, and d) adolescents lost in transition. Many members of the focus groups expressed a sincere wish to set goals in their clinical practice that were easy to integrate into the children's day-to-day life, but experienced this as a great challenge. Goals were set based on the results of the assessments made by the professionals in the focus groups, mostly solely by the different professionals. Sometimes goals were set based on the local therapists' statements. Goals were discussed during team meetings, however they were mostly brought to the meeting as information. Parents were not always present during these team meetings. In one university hospital a modified Goal Attainment Scale (GAS) (Kiresuk et al., 1994) was used as a pilot experiment with some children. The focus group in that hospital agreed during the discussion that GAS had enhanced collaboration with the parents and brought the goals closer to the children's day-to-day life. Collaboration with professionals outside the hospital environment occurred in different ways. Local therapists were sometimes contacted by phone prior to or during the child's hospital visit, but mostly the focus group members utilized the statements written by local therapists. However, they did not always have the local therapist's statements available when meeting the child. With the day-care centre professionals some collaboration occurred. The collaboration was either by written statements from the day-care teacher, by phone contact or by someone from the focus groups visiting the day-care center or someone from the day-care centre visiting the hospital during the child's hospital visit/stay. However, when the child entered school, the collaboration slowly faded and the responsibility for being in contact with the school professionals was handed over to the local therapists.

TRANSITION AS PART OF THE REHABILITATION PLANNING

The planning for the child's transition to school varied depending on the local/regional school arrangements. In two focus groups, the planning for starting school was handled by professionals in a special school in the region. In these hospitals the teams co-operated with the special school professionals at the beginning of the process. For children who have intellectual disorders or severe learning disorders the transition is led by a statute and the procedure has a

clear routine. The focus groups experienced that the procedure for these children was better in all respects as the process was clear and the collaboration during the transition planning with both parents and professionals from the special care units was close. The adolescents' transition to adulthood had no clear routine. Planning for the transition usually started about one year in advance, and consisted of preparing the written documents needed for the transition and contacting the adult health-care unit. The adolescent and his/her parents were involved in the planning procedure, but when the adolescent had moved to adult health care, the team members did not know how the rehabilitation in adult health care continued (or if it continued).

The ICF-CY was known among the professionals in the focus groups on a general level, and some individual professionals in the groups had tried to use it. Lack of time was the most common explanation for not using ICF-CY and in none of the university hospitals was ICF-CY in formal use.

THE DOCUMENTED OUTCOME OF THE REHABILITATION PLANNING PROCESS

In Study IV the interrelation between the children's needs and functional difficulties and the therapeutic goals documented in the written rehabilitation plans was investigated. The rehabilitation plans contained written statements from the multidisciplinary team members responsible for the rehabilitation planning, i.e. physicians, physiotherapists, occupational therapists, speech and language therapists, social workers and neuropsychologists. Beyond the multidisciplinary team members, also statements from private practitioners, i.e. local therapists working with the child in the child's home region were included. All together 393 written documents of 70 children were analyzed using ICF-CY as a reference.

The functional difficulties were described in detail and therefore also contained several ICF-CY components and categories. For the children in the age group 5-6 years, functional difficulties were described most particularized with a significant difference in relation to the age group 11-12 years (mean difference 6.4, 95% Confidence Interval (CI) 0.82 to 11.9, $p=0.018$). The children's and adolescent's needs were rarely explicitly expressed, rather were the needs expressed within the description of functional difficulties and thus were not always interpretable. The goals were not well reflected in the descriptions of the functional needs and difficulties. There were no significant differences in the content of the ICF-CY components between the functional needs/difficulties and the goals for the different age groups (Figure 5), neither were there significant differences between the ICF-CY components of the functional needs/difficulties and the goals in relation to the GMFCS levels (Figure 6).

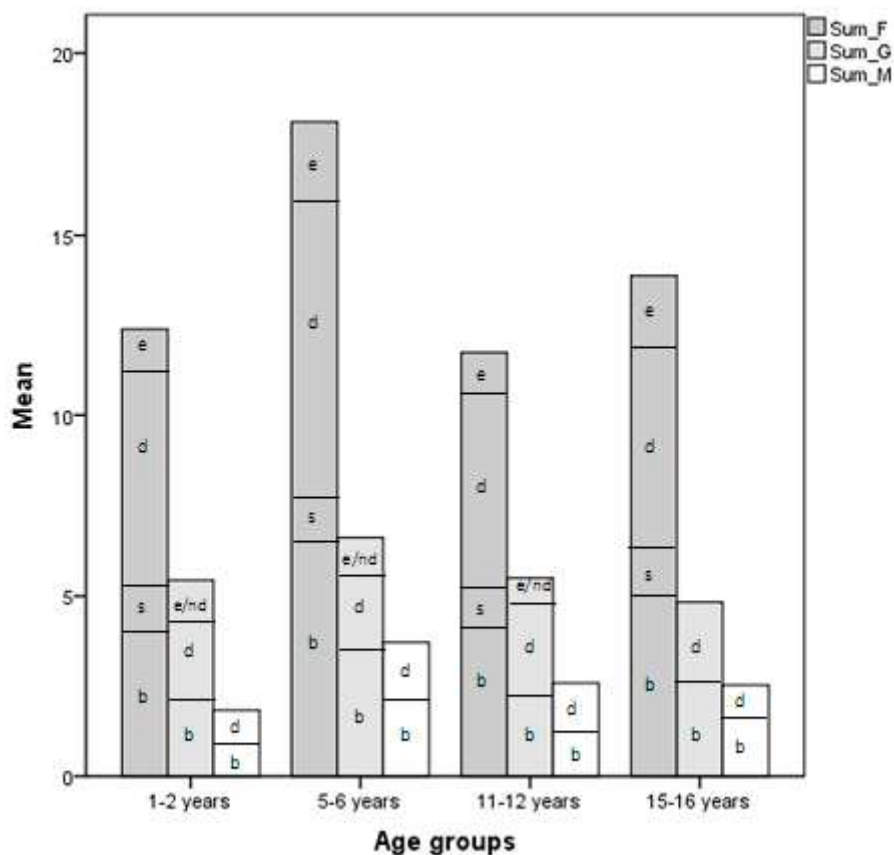


Figure 5. The mean of the total sum of ICF-CY categories described in the rehabilitation plans for functional needs and difficulties (Sum F), for goals (Sum G) and for matches (sum M) in the different age groups. b = Body function, s = Body structure, d = Activity and Participation, e = Environmental factors, nd = not defined (by any component in the ICF-CY)

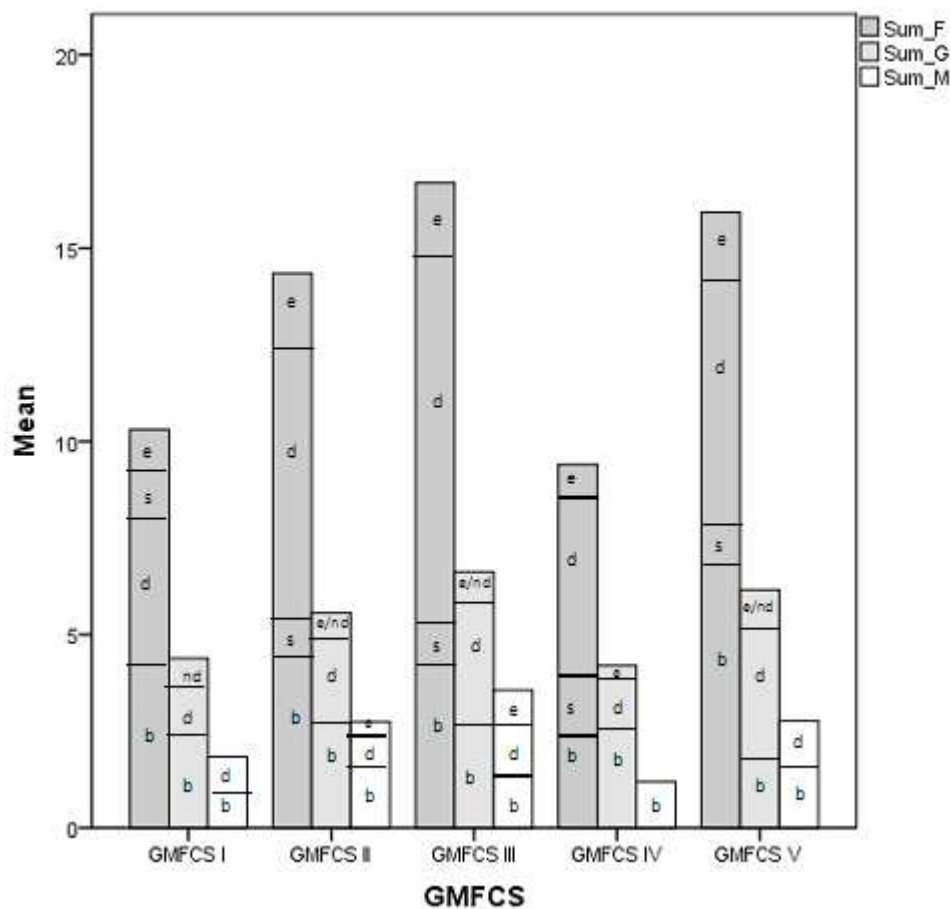


Figure 6. The mean of the total sum of ICF-CY categories described in the rehabilitation plans for functional needs and difficulties (Sum F), for goals (Sum G) and for matches (sum M) in the different GMFCS levels. b = Body function, s = Body structure, d = Activity and Participation, e = Environmental factors, nd = not defined (by any component in the ICF-CY)

Physiotherapy was the most frequent therapy recommended to the children and youth in all age groups. The highest amounts of physiotherapy were recommended for children in the age group 1-2 years (mean 88.0 times/year) and in GMFCS level III (mean 88.6 times/year). Occupational and speech and language therapy was mostly recommended to the age group 5-6 years (OT mean 46.3 times/year, SLT mean 39.2 times/year). Physiotherapists were also most frequently present during the team meetings when the children’s rehabilitation plans were set. The multidisciplinary teamwork was documented in 43% (n=30) of the rehabilitation plans. Statements from local therapists of different disciplines were added to the rehabilitation plan.

6 DISCUSSION

Previous literature discussing rehabilitation services for children and youth with CP highlights four important aspects to be included in the services. First, there is an emphasis on the family-centred approach in which the family is an equal part of the decision-making process on rehabilitation, and the uniqueness of the family and their needs are respected (Dunst et al., 1991; King et al., 2004; Bamm and Rosenbaum, 2008; Rosenbaum, 2011). Second, the multifaceted and heterogenic issues facing the child with CP, as well as his/her whole family, are a basis for recommending multidisciplinary teamwork in the rehabilitation services for children and youth with CP (Yerbury et al., 1997; Westbom et al., 2003; Veijola, 2004; Rosenbaum et al., 2007; Dodd et al., 2010; Launiainen and Sipari, 2011). Third, there is an emphasis on shared interdisciplinary goals that are meaningful for the child and the family and which focus on the child's success in completing activities, functioning and participation in everyday life (Ketelaar et al., 2001; Ahl et al., 2005; Löwing et al., 2009). In Finland goal-setting is considered to be a fundamental part of the rehabilitation planning process (Autti-Rämö, 2008; Rissanen, 2008). Fourth, CP is a permanent condition and persons with CP need lifelong rehabilitation. Accordingly, they face several important transitions or periods of change during their life. Systematic follow-up programmes are needed, and a future-oriented approach ought to be part of rehabilitation services (Jahnsen et al., 2004; Young et al., 2010; Rosenbaum and Gorter, 2012).

As part of the comprehensive research project focusing on developing rehabilitation services for persons with disabilities in Finland (the SII, see page 1 and 20) the purpose of the studies in this thesis was to explore and describe the family-centredness in services and the rehabilitation planning procedure for children and youth with cerebral palsy.

6.1 GENERAL DISCUSSION OF THE RESULT

This study is the first focusing on professionals' view on the rehabilitation practice for children and youth with cerebral palsy in Finland. The results reveal several aspects that can be defined as good practice but also aspects in need of improvement and development. The discussion focuses on areas in need of development which could be improved without major course.

Awareness and acceptance of critical issues in need of changes are a start of improvement and development.

IDENTIFIED FAMILY-CENTREDNESS

Professionals in multidisciplinary teams and local physiotherapists rated their FCS as moderate on the MPOC-SP (Study I). Local therapists rated their FCS generally slightly lower than the professionals in the multidisciplinary teams with a significant difference in “Providing General Information”. All professionals rated provision of general information as low. General information includes factors such as providing support to help families cope with the impact of their child’s disability, providing advice on how to get in contact with other parents, and having available information in the form of booklets or brochures on general concerns i.e., financial assistance, assistant programmes, dating, and sexuality. This also includes providing opportunities for the whole family to be part of the FCS. The identified uncertainty on how to collaborate with the parents might be reflected in how general information was provided. Social workers rated higher in providing general information than other disciplines. This points to their role in informing about financial costs and assistance, counselling parents on where to get information and advising about available assistance programs. However, the professionals seemed to be bound to their disciplinary roles, a fact that might lead to uncertainty of who should provide what kind of general information. General information supports families in getting an overall picture of what services are available, and in that sense also supports their opportunities of empowerment (Buran et al., 2009; Darrah, 2012).

General information was identified as poorly delivered also by parents. Being able to collaborate with professionals as a whole family, including siblings, has been reported to be important in a FCS approach (Guyard et al., 2011; Whittingham et al., 2012). In FCS, the collaboration includes seeing the family as the constant in the child’s life (King et al., 2004) where the child’s development occurs in a continuous interaction with the family and the environment. In other words, the child’s essential context is the family (Bronfenbrenner, 1989; 2005). However, indirectly the parents' work situation, financial situation, the rehabilitation resources and the rehabilitation organization can influence the family situation (Bronfenbrenner, 1989). Taking the whole family into consideration gives the possibility to discover strengths and needs to be able to support them in their parenting. Parents who feel empowered in their parenting capabilities are also more likely to provide their children development-enhancing learning opportunities (Dunst, 2007). Uncertainty of how to engage parents in the rehabilitation planning process might also lead to professionals concentrating on the child only. Koskinen &

Staufenbiel (2007) studied parents' discussions on the internet about having a child with a disability. The parents expressed disappointment in not being provided with physical or psychological support for the whole family. They queried all rehabilitation was provided only for their child, while they as parents, required support as well.

General information also included providing information of how to come into contact with other parents. Parents have a great need of sharing experiences and getting support from other families in a similar situation (Tonttila, 2007; Altmann, 2007). The parents of a child with a disability can be excluded from the category of friends they used to be in touch with before the child was born (Tonttila, 2007). The shortage of general information provision in services is not unique for Finnish conditions. Our findings are in accordance with several other studies (Raghavendra et al., 2007; Wilkins et al., 2010; Dickens et al., 2011; Schreiber et al., 2011; Bellin et al., 2011). Providing general information seems to be overall challenging in the service delivery for children and youth with disabilities.

PARENTAL VIEW ON FCS

Overall parents rated the service provided as moderate. The provision of "Coordinated and Comprehensive Care" was rated high by parents. To this factor belong items like planning together, so that all professionals are working in the same direction, providing information that is consistent from person to person, taking all needs of the child into consideration and confirming that at least one professional has worked with the child for a longer time (King et al., 2004). The parents experienced the services as co-ordinated and that their child's needs were taken into account in the rehabilitation and care processes. Professionals in turn experienced that the voice of the child was not heard. According to the documented rehabilitation plans, the child's and family's needs were not noticed in the rehabilitation planning process. A recent study on parents' experiences of the rehabilitation planning process, however, showed that the rehabilitation plan had fulfilled the needs of the child fairly well (Järvikoski et al., 2012). These partly conflicting views might depend on how parents and professionals understand the content and meaning of needs. Parents might experience that taking children's needs into account is related to the amount of therapies provided. On the other hand, professionals and parents might discuss aspects concerning the child's needs which are not documented in the rehabilitation plans. The MPOC questionnaire does not provide a deeper understanding of how parents reason about this issue, nor how they define the child's needs.

Parents did not have the possibility to choose when and what kind of information was provided. The lack of routine in how to involve the parents and the practice in which professionals discuss the child's and family's needs first by themselves, might lead to a situation where professionals deliver the pre-discussed information rather than listen to and discuss with parents. Lack of time was mentioned by the professionals as one reason for not guiding and informing parents. Lack of time is often derived from a requirement of financial profit or effective care management. An important part of the FCS is to provide well-co-ordinated and well organized services. This requires that the managers and the organizer have integrated FCS into their values, i.e. in strategies and mission statements (Dodd et al., 2009; Darrah et al., 2012). If the service is too professionally based and the organization built on biomedical values the service tends to be predetermined either by professionals or by organizers. This in turn can mean that the families become clients and the child a patient, and they all have to fit in with the type of services that are provided. To be relevant for the individual child and family, the services should be planned to fit their specific needs (Law et al., 2003).

MULTIDISCIPLINARY TEAM AS PART OF THE REHABILITATION PROCESS

In this thesis the work of multidisciplinary teams was not primarily studied. However, as the participants were mainly members of teams consisting of various professionals and the rehabilitation planning process as well as family-centredness was studied, the multidisciplinary teamwork was indirectly explored. It turned out that, when the members of multidisciplinary teams had the possibility to sit down and without hurry discuss issues based on multidisciplinary team-work, there was a diversity of opinions on the understanding of multidisciplinary teamwork. Based on the results in Study III and IV, it seems that the multidisciplinary work in the neuropaediatric wards at the hospitals was indeed teamwork defined as multidisciplinary (Choi and Pak 2006). The team was led by a physician (according to Finnish legislation) and seemed to be quite hierarchical in nature, where each professional worked mainly as an independent expert who assessed, set goals, determined an intervention and evaluated separately. The team members acted mainly within their own professional curricula and worked independently of the others, but they also collaborated to a certain extent. The collaboration with others in the team seemed to be mainly through team meetings or informal discussions. The team members' co-operation with other professionals in the child's life, like local-therapists or school and day-care professionals was mainly by receiving written statements, although some co-operation by phone and by meetings occurred. Some team

members had phone contact to the external professionals and from one team a team member visited day-care when needed.

AN INTERDISCIPLINARY APPROACH

Previous studies in Finland concerning co-operation or collaboration between all involved in the child's everyday life defined collaboration with the child's needs as a base for networking (Sipari, 2008; Launiainen and Sipari, 2011). A model of networking was presented and effort to work according to the model was introduced in a few municipalities during the last years (Sipari, 2008; Launiainen and Sipari, 2011). However, to be able to network the work in the rehabilitation planning, hospitals must change from a multidisciplinary model to an interdisciplinary or even transdisciplinary way of working. In an interdisciplinary teamwork model, the family is listened to, and the needs are discussed together in the team. A constant interaction of findings and recommendations between the team members is part of the approach. Goals are set together with the family and the intervention plan is made in collaboration. A closer collaboration and a respect towards all the members of the team are part of the working model. Local therapists would be part of the team or invited to the team meetings. A change from a multidisciplinary to an interdisciplinary approach could increase teamwork and team effectiveness as well as enhance work satisfaction (Roelofson et al., 2001; Körner, 2010). To develop the collaboration between all involved in the rehabilitation process, the use of a named contact person is recommended, and a co-ordinator responsible for the communication between all involved. He/she would be a link between the hospital, i.e. the rehabilitation planning unit and the local units (i.e. day-care, school, local therapists, municipality and SII) – i.e. a case manager.

GOAL SETTING IN REHABILITATION PLANNING

The findings in this thesis highlight some insufficiencies in the goal-setting procedure. Firstly the set goals were not related to the described functional needs and difficulties; secondly there was no clear routine in how parents were involved in the goal-setting procedure; thirdly the documentation of the child's functioning and the goals were mainly focused on impairments. Finally, often goals were set both by the local therapists and the staff at the hospital, responsible for rehabilitation planning, but the collaboration was scanty.

GOALS IN RELATION TO NEEDS AND FUNCTIONAL DIFFICULTIES

The multidisciplinary approach, where professionals set goals related to their professional disciplines, might explain the findings that goals and functional needs and difficulties were weakly related. The rehabilitation plans, including statements from local therapists, contained detailed descriptions of the child's body function and activities, whereas the goals were either broadly defined or vague. When the goals focused on body functions or activities, they rarely corresponded to what was described in the needs and functional difficulties of the child/youth. Therapists usually strive for functional goals (Darrah et al., 2008), but also tend to define function as treating impairments (Rosenbaum and Gorter, 2012). The detailed documentation of the bodily aspects indicates a medical focus in rehabilitation. In a medically focused rehabilitation, children's impairments are treated. Rosenbaum stated (2011) that in a medically focused rehabilitation, the set goals are biomedical, the recommended treatments are according to these biomedical goals, and the outcomes are evaluated by looking for biomedical improvements. It seems that professionals in the rehabilitation settings for children and youth with CP in Finland are working in a biomedical way. Some of the participants in the focus groups in Study III discussed the difficulty of setting explicit goals as they experienced it difficult to think beyond their own professional curricula. A previous study on early intervention programs often used by therapists (NDT, Vojta, Conductive education, IHDP, IHAIP) found that the approach in all the programmes was focused on the child to improve functioning. Some of the programmes strived to take the importance of environmental factors for the achievement of everyday activities into account, but the impact of treatment was mainly biomedical (Dirk and Hadders-Algra, 2011). The NDT approach has traditionally had a strong position in the therapy approach for children and youth with CP in Finland, which might explain the biomedical disability focused approach observed in the documented rehabilitation plans.

Recently, different therapy approaches were developed to enhance the focus on goals in therapy. Goal-directed, activity-focused therapy is based on needs, defined by the child and the family and is focused on motivating the child to be active in his/her everyday environment. Goal activities are practised in the environment where the child will use the skills and individual training is combined with group training to support peer learning. The approach has proved to improve everyday activities in preschool children (Ketelaar et al., 2001; Ahl et al., 2005; Löwing et al., 2009; Löwing et al., 2010; Størvold and Jahnsen, 2010; Law et al., 2011). A

change from a biomedical approach to a more goal-directed activity focused approach would enhance the possibility for the professionals in our study to match functional needs with goals and interventions in collaboration with the family.

PARENTAL INVOLVEMENT IN THE GOAL-SETTING PROCEDURE

Parental involvement in the planning and goal-setting was documented in half of the studied rehabilitation plans, but the needs of parents were rarely documented. Parental presence in about half of the cases is in accordance with a previous study in Finland, where approximately half of the parents reported participating in the rehabilitation planning process (Järvikoski et al., 2012). Being part of the goal-setting team has by parents been expressed as positive, self-confidential and motivational (Øien et al., 2009). In the study by Järvikoski and co-workers (2012), the child's age, involving parents and listening to their needs, as well as active participation of the rehabilitation counsellor, therapist and day-care/school professionals were all positively associated with parental satisfaction. Also the experience of having been heard during the process had a strong relation to the feeling of satisfaction with the service (Järvikoski et al., 2012). In our study, parents were often actively present when the therapists assessed the child. It remained, however, unclear how parents' expertise in their child's abilities and needs was recognized. The importance of parents being part of the goal-setting and decision-making has been highlighted in several studies (Wiart et al., 2010; Rosenbaum 2011; Darrah et al., 2012). However, parents do not always want to take the responsibility for goal-setting, since they might fear having limited knowledge about the child's needs and that the child therefore might not get the relevant rehabilitation (Wiart et al., 2010). Good listening ability and a supportive approach are required to empower parents to participate in goal-setting and express their requisites. In our study, professionals felt unsure of the parents' role, which indicates that the professionals also might need support in how to engage parents in the rehabilitation planning and goal setting.

DOCUMENTATION

As rehabilitation financers, as well as professionals involved in the child's therapy, are dependent on written statements, it is important that they are clearly written. In the rehabilitation plans the functional level of severity GMFCS (Palisano et al., 1997) was used in

about half of the rehabilitation plans. The needs of the child in terms of meaningful life tasks were not expressed. A shift from the detailed descriptions of body functions to defining the level of severity and hand function as well as the activities needed for optimizing home and community participation and self-determination is recommended. To improve the written documents, an instrument to facilitate team discussion and optimizing phrasing and documentation, could be used. Different instruments to help parents and professionals in goal setting and intervention planning discussions have been presented (Roelofsen et al., 2002). However, an instrument as such does not necessarily enhance rehabilitation planning and goal-setting (Nijhuis et al., 2008b), but it can provide a starting point for standardized processes (Darrach et al., 2012). The benefits of the combined use of Canadian Occupational Performance Measure (COPM) and the Goal Attainment Scale (GAS) as well as the combined use of GAS and ICF-CY, were recently emphasized in a study by Ostensjø et al. (2008) and McDougall and Wright (2009).

TRANSITIONS

During the development from infancy to adulthood the person faces several transitions, such as starting day-care, school (preschool, primary and secondary school, high school), professional studies and transfer from child health care to adult health care.

This thesis identified examples of transition phases of good practice in which collaboration with various parties occurred (i.e. transition to day-care and special care units). The focus on children's transition to day-care was supported by the results in Study IV, where functional difficulties and needs for children in this age-group were described with great accuracy. There was also a focus on pre-school goals, like readiness for school. These findings are supported by previous studies where parents experienced that communication and information with professionals, good relationships and helping families to find the best solution were keys to a smooth transition (Rous et al., 2007; Meyers 2007; Podvey 2010). Meyers (2007) studied a model where local therapists were responsible for carrying out the intervention at school in effective collaboration with the hospital team in charge. The team members acted as consultants and the local therapists as facilitators of the transition. Most of the professionals involved were satisfied with the model. A similar model could be observed in one of the studied hospitals, where professionals were visiting day-care and vice versa and the local therapists were to some extent involved in the collaboration.

Among the multidisciplinary teams there was a general concern of how rehabilitation goals were taken into account at school. The responsibility for implementing rehabilitation goals at school was handed over to local therapists. However, goals for school-aged children and youth (11-12 and 15-16) were focused on body function and activity. A change in impairment might not necessarily lead to a change in the child's participation in everyday life (Rosenbaum and Stewart, 2007). Accordingly, feedback from young adults has highlighted the fact that concentrating on impairment in childhood rehabilitation does not help them to manage their lives in adulthood (Stewart et al., 2001). As the collaboration with local-therapists was irregular, the question of how meaningful goals and interventions could be planned according to the child's actual needs at school needs to be raised.

In none of the hospitals transition to adult-health care was well organized; adolescents were lost in the transition. The adolescents were rather handed over to the adult health care than transferred with mutual confidence. In the documented rehabilitation plans, the challenges of the future were rarely mentioned in the age-range between 15-16, and the goals did not reflect such a stand point. A weakness in the link between child health care and adult health care is not unique to Finnish circumstances. It is a global problem that child health care and adult health care are different worlds and that the adolescents experience the transfer to adult health care as "falling off a cliff" (Young et al., 2006; Nieuwenhuijsen et al., 2008; Young et al., 2009). Martin (2009) found that Finnish adolescents with disabilities experienced that they participated and that their voice was heard in the rehabilitation planning process. However, some adolescents experienced also that, even if they were listened to, their opinions were not taken into account and the decisions for rehabilitation were professionally based (Martin 2009). Giving youth and young adults with CP a possibility to express their experiences of transition to adult health care and the years after are important. Consequently further studies on the topic are needed.

For children with learning disabilities and intellectual disorders there was a clear routine and a co-ordinated planning procedure in collaboration with the family prior to the transition. The multidisciplinary team members' experience of this was due to the fact that there is a statute for mandatory services at the special care unit taking over the child's rehabilitation services. The routine at the hospitals prior to the transition to the special care units was an example of good practice which might be able to transfer to other transition phases.

Helping children and their families experience successful transitions across any programme requires careful planning, child and parental involvement in the decision-making, knowledge of everyone's role and responsibility in the transition processes as well as a focus on strategies for managing in future life all the time.

THE USE OF ICF-CY

The ICF-CY was familiar to the professionals on a general level; however, it was not formally used. Lack of time was presented as the main reason for not using ICF-CY. A great number of ICF-CY components and categories were used in the documentation of the rehabilitation plans, i.e. when describing the functional difficulties and set goals. Especially body functions and structures were largely used, but also different activities were described. This finding is in accordance with previous studies analyzing health documents (Ståhl et al., 2011; Klang Ibragimova et al., 2011). Many goals were too broadly defined and therefore could not be linked to an ICF-CY code. This finding is in accordance with the study by Ståhl and co-workers (2011), in which several health terms were too broad to link to the ICF-CY. The wordings in the rehabilitation plans were mostly written in a discipline-based way. This way of writing was highlighted by Strogilos and Xanthacou (2006) who observed that documentations made in a professional context may also be formulated in a discipline specific language and thus not understandable by the family.

As a common language ICF-CY has shown its benefits to support professionals to facilitate discussion and to strengthen their team roles. Today there is a general knowledge of the importance of a common standardized language between professionals (Ibragimova et al., 2009). The terminology of the ICF-CY can be used not only to facilitate discussions in the team, but also as useful practical guide for parents and professionals when priorities for assessment, goal setting and treatment are being determined. It provides a broad conceptual framework to understand the health conditions of CP (Imms et al., 2010). It is important however, to remember that ICF-CY cannot replace professional language, but it can serve as a complement and a tool for communication (Adolfsson, 2011).

Using ICF-CY as a model can support therapists and rehabilitation professionals in general in their clinical decision making. It is crucial to take all the constructs into consideration in the rehabilitation planning process and explore also the causal links considering the contextual factors (Paltamaa, 2008). The child's and the family's own subjective experience is essential for

appropriate rehabilitation planning. Subjective experience of involvement as an expression for participation has been studied by Granlund et al., (2012) in the form of a third qualifier measuring subjectivity. The environment where the child spends most of his/her time in everyday life is the source for development, learning and rehabilitation, i.e. home, day-care, school, during leisure activities (Pless et al., 2011). The persons who are part of the child's everyday life also know the child's needs best and should therefore be included in the planning process. To enhance this communication, ICF-CY can be an excellent tool.

In a study by Klang and co-workers (2012) the use of ICF-CY was evaluated by analyzing rehabilitation plans made before and after in-service training of ICF-CY. The study showed that there was a larger number of ICF-CY codes used in documented rehabilitation plans after ICF-CY training. However, the ICF-CY codes used were mainly on 3rd and 4th level for Body functions and Activities/Participation. Other studies have found clearer benefits of the implementation of ICF-CY after training (Pless et al., 2009; Adolfsson et al., 2010). Adolfsson (2011) suggested that professionals should know the chapters on at least the first level. For multidisciplinary use a selection of 2nd level is recommended, whereas categories on the 3rd and 4th levels are useful only in in-depth discipline-specific use.

In clinical settings ICF-CY can be used as an tool for need assessment, a goal identification tool, to facilitate dialogue or discussion between families and professionals as well as a documentation tool (as a taxonomy or to defining functioning) (McDougall and Wright, 2009; Dodd et al., 2010; Pless and Granlund, 2011; Rosenbaum and Gorter, 2012). To enhance and facilitate the use of ICF-CY, some tools were developed. Accordingly, some tools developed for ICF might be appropriate to use for children, and there is an ongoing development of new aspects and tools. The ICF-CY questionnaire was tested to be feasible and useful in assessment and intervention (Ibragimova et al., 2009). The ICF Checklist, the ICF Categorical Profile sheet, the ICF Assessment sheet, the ICF Evaluation Display (WHO) as well as the Rehabilitation Problem-Solving Form (Steiner et al., 2002) have been developed from the ICF, but might be feasible also for pediatric settings. However their use or modification for children should be studied. New aspects of ICF-CY have been studied and are under development, i.e. code sets for everyday life situations as a basis for child participation in everyday life situations (Adolfsson 2011). However, to our knowledge there is no core set for children and youth with CP under development yet, though this might be clinically useful.

PARTICIPATION

In a recent Finnish study, parents did not experience participation as an important factor for satisfaction with the rehabilitation planning process. Rather, the parents were satisfied if the child was heard (Järvikoski et al., 2012). These results might depend on how the term participation is understood. It is unclear whether participation for the parents meant that they are physically present, as exemplified in Study III and IV, or whether it meant being an active participant of the team, i.e. having the possibility to take part, be involved, have equal responsibility for the planning process and be listened to.

For a child or an adolescent with functional difficulties, the severity of limitation in physical ability might be barriers for participation (Van Naarden Braun et al., 2006; Parkes et al., 2010). Furthermore, participation has been reported to decrease with age for adolescents and young adults with disabilities (Pollock and Stewart, 1990). The professionals in Study III brought the term learned passivity to discussion, i.e. the child is not heard during the rehabilitation planning process and learns to rely on others' judgments about rehabilitation, goals and interventions concerning aspects in their life. The child is most central to the FSC, being the person to which the care and treatment are focused (Kelly et al., 2012). Kelly et al., (2012) found that adults are not aware of children's capacity to participate in their own health-care decisions, and that children's potential is often underestimated. They concluded that it is no wonder that confusion exists among health-care professionals about how to best involve the child in the decision-making process. Not letting children participate enhances their helplessness and dependency on adults.

The goal-setting process has, for example, been assumed to be too abstract for a child and several instruments to support the identification of priorities and set goals have been developed. These instruments have, however, been developed for parental participation and support. If the goals are set by others, children have ascribed outcomes after interventions owing to others' actions rather than changes in their own ability (Missiuna et al., 2006). An instrument designed for children to set their own goals is the Perceived Efficacy and Goal Setting System (PEGS). The PEGS is composed of 24 items, representing everyday activities, which are presented to the child on picture cards in pairs. The child chooses which picture of two is most like him/her. The PEGS is one example of how to involve the child in the goal-setting process (Missiuna et al., 2006).

THE PATHWAY TO PARTICIPATION FOR CHILDREN

Arnheim (1969) had the supposition that participation through an empty ritual without power is a frustrating process for the powerless. Based on this supposition, he developed the model “The Ladder of Participation”. The ladder is a typology of eight levels of participation with each stage corresponding to the power in determining the outcome. The Ladders of Participation has been adapted to a children’s view by Roger Hart (1992;1997). There have, however, been some critics against the ladder models, as ladders are seen as symbolizing climbing from a lower level to a higher where the top is the level to strive for (Sinclair, 2004).

Harry Shier (2001) developed a Pathway to Participation model based on Hart's (1992) Ladder of Participation. The Pathway to Participation model does not consist of the non-participation levels, but starts from the assumption that children are listened to. The model has five levels of participation: 1) children are listened to, 2) children are supported in expressing their views, 3) children’s views are taken into account, 4) children are involved in decision-making processes, and 5) children share power and responsibility for decision-making. Each level has three stages of commitment: i) an opening possibility, which occurs as soon as a professional has decided or made a statement to himself/herself that he/she is intended to listen to the child. Though, opening here might mean that the opportunity to make it happen may not be available because of i.e. organizational or management barriers. ii) Opportunity occurs when the worker or organization is able to operate at this stage of the pathway in practice. The resources (including staff time), skills, knowledge and new procedures or approaches (might be through training or staff education) has been established. iii) Obligation occurs when it is a question of agreed policy in the organization. It becomes an obligation on the professionals that they should work this way. Enabling a specific level of children’s participation is “built-in” to the system.

The model provides questions at each level and stage to help professionals and organizations to decide the level to work towards (Shier, 2001) (Appendix 1). Children need to learn about and get an understanding of their life circumstances and future life situation, and in particular how to articulate their life needs, i.e. needs beyond their impairment needs.

6.2 METHODOLOGICAL CONSIDERATIONS

Family-centredness among professionals working with children and youth with CP was not previously studied in Finland. To reach as many professionals as possible, a survey was

conducted. Rehabilitation for children and youth under 16 years of age with CP is planned and followed up at the hospital within which area the child lives. For those children attending a special school, the school is responsible for rehabilitation planning and follow-up. The population was all multidisciplinary team members in all the central and university hospitals in the country as well as the multidisciplinary team members in the three largest government special schools. Furthermore, physiotherapists who worked as private contractors, who had an agreement with SII and who had informed being involved in the physiotherapy for children and youth with CP were invited to participate. During the same timeframe as Study I, there was an ongoing study at two university hospitals with the purpose of identifying a valid outcome measures to be used in rehabilitation for children with CP. As part of that study, parents of children with CP were invited to evaluate the family-centredness at the hospital wards. We consider that the participants in these four studies capture the major part of persons involved in the rehabilitation process of children with CP.

The choice of MPOC as the questionnaire used was based on previous literature (ONeil and Palisano, 2000; King et al., 2004; Bjerre et al., 2004; Stewart et al., 2004; Dyke et al., 2006; Raghavendra et al., 2007; Siebes et al., 2008a). The MPOC has frequently been used in studies with the target group of children with CP, and could be used to compare professionals' and parents' experience of the family-centredness in services. The MPOC for Service Providers as well as MPOC-20 have shown very good internal consistency, test-retest reliability and validity (Woodside et al., 2001; King et al., 2004). Also translations to other languages than English have shown good test-retest reliability and validity (Siebes et al., 2006; Siebes et al., 2007; Saloojee et al., 2009). To ensure confidentiality of professionals, the questionnaires to the hospitals and special schools were sent to the senior physician to further distribute to the team members. The questionnaires to the local physiotherapists were sent by clerks at the SII.

To be able to get a closer insight into the rehabilitation-planning procedure and process a focus group method was used in Study III. As the university hospital, the multidisciplinary team meet a considerable number of children and youth with CP in the country and they cover regionally all the country, a purposive sample was used. A focus group is defined as a group of people with similar background and experience, who are experts on the topic of interest (Greenbaum, 1998; Krueger and Casey, 2009). The focus group provides qualitative data during a strictly planned group discussion aimed to give insight into the stated problem (Krueger and Casey, 2009). The members of a focus group interact with the interviewer and each other and do not need to agree or come to a conclusion in the discussion. For the researcher the goal is to

understand the reality of the group members in the context studied (Holloway and Weeler, 1996). The ideal size of a focus group is five to eight people, but traditionally a group can be up to 12 people (Krueger and Casey, 2009). The size of the focus groups participating in our study was eight to twelve persons, but we considered it important that all disciplines represented in the multidisciplinary team had the possibility to participate. To strengthen trustworthiness and creditability in the study, efforts were made to understand the underlying social context under study, to let the voices of the participants be heard and to make sure everyone in the group had the possibility to participate in the discussion.

The analysis used was content analysis, and to ensure trustworthiness the researchers returned to the transcriptions and discussed the text on several occasions. The focus in this study was on understanding the experiences of the multidisciplinary teams at the university hospitals. The study had a qualitative epistemology, but it was not guided by any of the traditional qualitative philosophical assumptions, and therefore the methodological approach adopted was generic (Caelli, 2003). Not using a traditional qualitative philosophy might be seen as a weakness in the study, but the use of a generic qualitative approach has been discussed among qualitative researchers in recent last decades as a methodological approach for use. It is however important to ensure rigor in a study using a generic qualitative approach. Caelli (2003) argues that, even if using a generic qualitative approach, it is important to honour the “philosophical and methodological roots” of qualitative research. Four key areas to ensure the quality of qualitative research are presented: 1) the researcher should address his/her theoretical positioning, 2) address the congruence between methodology and method, 3) express strategies to ensure rigor, and 4) examine the data through an analytic lens. In this study an effort to address all these key issues has been taken. All these four qualifiers were carefully taken into account when designing and conducting the study.

The ICF-CY as a reference in Study IV was used for the possibility to compare with ICF codes the descriptions of functional needs and difficulties with the set goals. Furthermore, it gave the opportunity to compare the results with other studies using ICF-CY as a reference when analyzing texts. The linking rules according to Cieza et al., (2002; 2005) has shown to be usable for linking texts in goals (Mittrach et al., 2008) and rehabilitation plans and medical documents (Klang Ibragimova et al., 2011; Klang, 2012) even if the linking rules primarily have been used to link health-status measurements. The ICF Checklist with codes on the 1st and 2nd level have been used as a reference to link health status documents of persons with traumatic brain injuries (Koskinen et al., 2007). The importance to agree on how to link the text was noticed, especially

as the researchers represented different disciplines and it was presupposed that they looked at the text with different “eyes”. Kappa analysis was used to analyze the agreement between the raters, and as it was shown to be fair to good, a consensus agreement on the best linking practice was made. To strengthen the linking procedure, additional linking rules and previously used rules of overall and blurred expressions was used (Cieza et al., 2005; Adolfsson, 2011; Fayed et al., 2012).

LIMITATION OF THE STUDIES

To find the total number of team members in the hospitals and special schools the chief senior physicians were contacted. However, the number per profession or a clarification of the content of their work was not obtained, which resulted in our not being able to do an external drop-out analysis. The questionnaires to the hospitals and special schools were also sent to the chief senior physician who handed out the questionnaires to the team members. This procedure could have resulted in some of the team members never having received the questionnaire or some team members not working with children and youth receiving it. In Study II we separated the professionals at the two university hospitals who had participated in the survey in Study I, to be able to compare professional’s and parent’s view of the family-centredness at the same hospital wards. A weakness was the small participation rate at Helsinki university hospital.

We chose not to ask gender for in the questionnaires, as the majority of professionals working in multidisciplinary teams and as physiotherapy service providers/local therapists are female and combining region and gender would have increased the possibility to recognize the participants. The parents invited to participate did not inform about any background variables to ensure their anonymity. Therefore, no analysis of experienced family-centredness among parents in relation to the child’s age, gender, and level of severity or length of stay at the hospital ward could be conducted.

The local-physiotherapists who were invited to participate all had an agreement with the SII. As the SII finance rehabilitation for persons with severe disabilities, local physiotherapists taking care of children and youth with milder disabilities only (GMFCS I and II) might have been excluded from this study.

In the focus group discussions there is always a risk that someone in the group does not get his/her voice heard. In this study, efforts were taken to ensure that everyone had the possibility to speak. There were also risks that, especially as some groups were large, someone who had a

different opinion remained silent instead of bringing her/his opinion to the discussion. There were some hierarchical traditions left in some of the hospital wards, which might have led to someone remaining silent. Even though the researchers made efforts to understand the reality and the social constructs of the groups there might have been issues and cultures which the researchers did not understand thus resulting in bias in the reporting. All the focus groups that participated in the study represented university hospitals. The neuropsychiatric teams at the central hospitals might be smaller in size and have different issues in their everyday work, and therefore it would have been valuable to also have heard their experience of the rehabilitation planning process.

7 CONCLUSION, CLINICAL IMPLICATION AND FURTHER RESEARCH

The two main topics of the thesis were the quality of FCS and fluency of rehabilitation planning, and these can be concluded as follows:

Professionals in multidisciplinary teams, physiotherapy private practitioners and parents rate the family-centred service as fair to moderate. There was a difference in how professionals of different disciplines rated their FCS. Social workers and rehabilitation guides self-rated their provision of general information higher than others, whereas nurses rated their provision of specific information lower than other professionals. Work experience had an impact on FCS delivery. Professionals with more than 25 years of work experience rated higher values than those with less experience. The provision of general information was rated low by all, both by professionals and parents. Services like providing opportunities for the whole family to obtain information, to promote family-to-family contacts, having information in the form of booklets available and letting parents choose when to receive information as well as type of information were services in need of development.

In the rehabilitation planning procedure, professionals experienced goal-setting as challenging. Parents were involved in the planning procedure in several ways, but there were no clear procedures for when and how they were involved, and it remained unclear as to if the parents needs were met. The children seemed to be passive in the rehabilitation planning process. The principles of FCS were adopted, but the full implementation of the FCS philosophy is lacking. Collaboration with local therapists, day-care and school occurs mostly by written reports. In the transition to special health-care units there was a clear routine. To day-care and school there were some routines, but in the transition to adult health care there was no clear practice. The ICF-CY was not formally in use.

In the written rehabilitation plans the described functional difficulties were not well connected to the set goals. The ICF-CY categories Body functions and Activities were mostly used in the descriptions of functional difficulties. The children's needs were not explicitly described. Goals

were often vague. The presence of parents was mentioned in about half of the plans. Professionals of different disciplines were involved in the planning procedure.

CLINICAL IMPLICATIONS

An organizational support for a true FCS, with the possibility for professionals in the multidisciplinary teams to deepen their knowledge of the philosophy of FCS can provide as a starting point for improving FCS. Accordingly, developing routines in the procedures of goal-setting and the transition phases could contribute to enhancing quality in services. Every family is unique, and therefore FCS can never be routine, but the ways and means to involve and empower parents and especially children can be improved.

A shift towards a biopsychosocial approach and the use of a goal-setting instrument in combination with ICF-CY as a conceptual framework can enhance goal-setting procedure and documentation.

A coordinator or case manager could enhance rehabilitation service for families with children and youth with CP.

IMPLICATIONS FOR FURTHER RESEARCH

The results of this thesis raise the following questions:

- 1) what are the specific needs in the different transition phases during childhood?
- 2) how is the follow-up and rehabilitation organized for young adults with CP?
- 3) what is the personal experience of young adults with CP of their transition to adult health-care?
- 4) what kind of general information are parents to children and youth with CP longing for?

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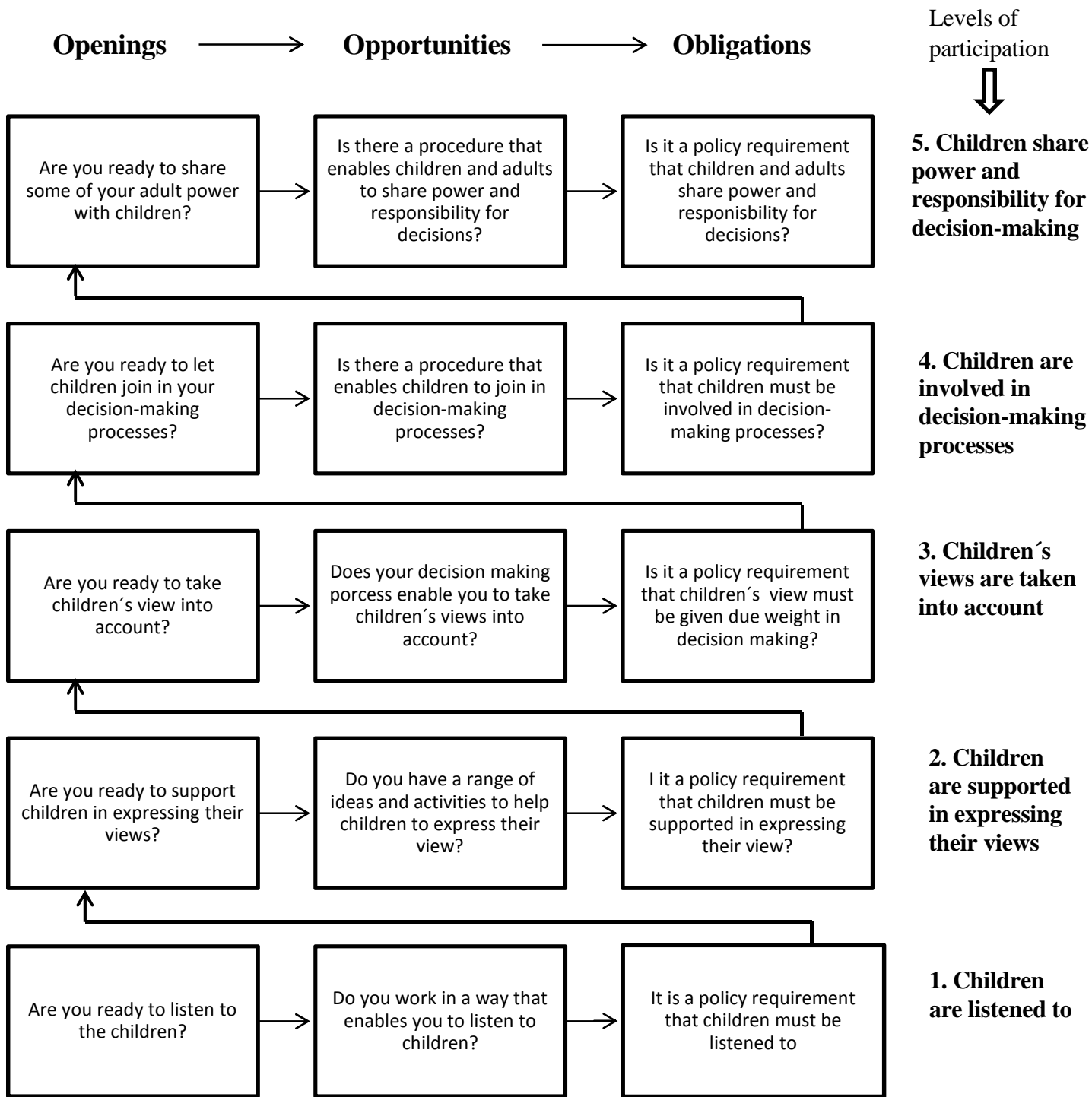
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Appendix 1. Pathways of Participation by H. Shier (2001). Printed with the kind permission of Mr Shier.