



**Karolinska  
Institutet**

**Institutionen för kvinnors och barns hälsa**

# Family-centredness in services and rehabilitation planning for children and youth with cerebral palsy in Finland

**AKADEMISK AVHANDLING**

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# 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 neuropediatric 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 neuropediatric 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 (ICF-CY). 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

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