



Rehabilitation processes, intervention and services for preschoolers with cerebral palsy (project D)

CHARM
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Project Group

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Theoretical perspectives

- Family-Centred Services as «best practice»
- Sociocultural perspective on child development and learning
- ICF as a conceptual model

Purpose

- To gain knowledge on child development in relation to habilitation processes and services in a family perspective,
- to identify determinants for changes in child activities, participation and quality of life in pre-schoolers with CP.
 - Such knowledge is essential for the development of effective interventions, follow-up programs and family centred services for pre-schoolers with CP.

Research questions

- What characterises habilitation interventions and services offered to preschool children with CP and their families in Norway?
- How is the developmental course concerning mastering, activity performance, participation in everyday life and quality of life?
- How are interventions organized in groups associated with child changes in activity and participation compared to interventions organized as individual training?
- How are families involved in interventions?
 - How is their active involvement in interventions associated with changes in the child's activity and participation?
 - How does their involvement in the development and implementation of interventions influence parent's perception of empowerment and quality of life?
- How do parents evaluate their child's benefit of interventions compared to measured child outcomes?
- How is the association between intervention costs and child/family outcomes?

Design and participants

- A national prospective longitudinal study including all habilitation units in deciding to participate

Subjects

- All new children registered in the National CP register (CPRN) or follow-up program (CPOP) will be invited.
- Inclusion criteria are children below 3 years of age, registered in CPRN/CPOP between 01.08.2011 until 31.07.2014.
- Exclusion criteria: None of the parents read Norwegian.

Data collection

- Assessments twice a year for three years in connection with the CPOP assessments
 - Parent reported interventions and services: type, frequency, organization, place, parental involvement and benefits
 - Child: characteristics, activities, participation, QOL, Coping
 - Family: Socio-demographic factors, family empowerment, QOL

Significance of the project

- The longitudinal data render a unique database for ...
 - In depth studies of specific questions
 - follow-up studies through school-age, into adolescence and adult life
 - comparisons with other groups of children with disabilities
 - International collaboration

Issues for discussion

- More intensive training for children with CP has been focused in clinical practice and research during the last decade. What is intensity ?
 - The amount of training? Frequency? Duration? Number of repetitions? Heart rate? Oxygen uptake? Load/strain? Organized training or focused activities in daily life?
- The research questions are the basic issues to be investigated. Other important issues and questions?
- What conceptual models and analyses are relevant to answer the research questions?
- How to evaluate costs of habilitation services in relation to outcome?
- The protocol has an assessment frequency of six months in three years for the participants. Are these intervals reasonable taken the children's age and the outcome measures into account?