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Factors facilitating family functioning in families of children with disabilities

- in the context of the Swedish Child and Youth Habilitation Service

AKADEMISK AVHANDLING

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ABSTRACT

At times it is a challenge for any family to balance resources, abilities, and needs. Challenges that tend to be enhanced when a child has an impairment. Family routines must function and be consistent with the family's ecology and be meaningful according to the family's culture. The family's coping with cultural-environmental, psychosocial, and socioeconomic stresses throughout the diverse phases of the family life cycle has been linked to healthy family functioning. Families that function well and experience health manage to find balance between growth vs. change and stability vs. equilibrium in relation to the exchange between the family as a system and its environment. Families of children with impairments are offered service and support through the Child and Youth Habilitation Services (C-YHS). Earlier only the child was the focus of interventions, but with a family centered perspective the whole family's well-being is concerned.

The overall aim of the thesis is to explore how families of children with impairments use resources aimed to enhance family functioning in relation to challenges in every-day life. This is examined in the context of the support provided by the Child and Youth Habilitation Services (C-YHS). The specific aims were 1) to investigate professionals' encouragement of parental coping strategies (Study I), 2) to compare the content of issues discussed at the planning meetings with the activities provided by the C-YHS (Study II), 3) to examine the design of a future study focusing on problem solving and how different problem solving styles are related to internal and external resources (Study III) and 4) to explore leisure activities patterns in families of children with profound intellectual and multiple disabilities (Study IV). Descriptive and explorative qualitative and quantitative study designs including longitudinal and cross-sectional studies.

The main findings were as follows. *Coping types and coping strategies* (Study I): families used four types of positive coping. The coping type goal-directed problem-focused was used most and this was also the type of coping that was most frequently encouraged by professionals. Families most used coping strategy was values and this was most often related to information and problem solving in professionals responses. *Planning meetings and activities implemented* (Study II): families concerns and problems raised at planning meetings set the agenda for activities and actions in everyday intervention. Decisions were also made between planning meetings and affected actions and activities performed in everyday intervention. On top of goals decided in planning meetings decisions were related to managing families' everyday activities. *Pilot study* (Study III): analyses of quality indicators of the Social Problem Solving Inventory indicated that it would be possible to discriminate between different problem-solving styles using the instrument in this sample. Result concerning the strengths and weaknesses of the planned web-based procedures showed that problems can arise when adapting questionnaires to a web-based survey, that it was a prerequisite that the family had an individual plan to answer many of the questions and that a stop function added had serious consequences for access to the survey if not completed at one point in time. *Involvement in leisure activities* (Study IV): families of children with profound intellectual multiple disabilities (PIMD) were involved in both core and balance family leisure activities, but to a lesser degree than families of children with typical development. The PIMD group showed a proportionally higher involvement in core family leisure activities than in balance activities compared to families of children with typical development.

Conclusions are to encounter stressors families need different coping strategies. Families' use of coping strategies is facilitated if they are encouraged by professionals that are aware of the families' values. Families of children with impairments have concerns about the future and problems related to everyday life. When families concerns and problems are considered by professionals and result in actions and activities, the more the problem solving becomes adapted to their actual needs in everyday life. Resources such as coping strategies and problem solving skills are important to make routines function, and also to enhance and enrich leisure activities where the family spends time together. Family functioning is a complex process where internal and external resources are interrelated. In order to guide the process of providing support to family functioning for families of children with impairments there is a further need for comprehensive measurements to capture the complex process of family functioning. In addition research is needed that connects different aspects of the process of support provision to outcomes for the family and child outcomes.