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Factors facilitating family functioning in families of children with disabilities

- in the context of Swedish Child and Youth
Habilitation Service

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Att våga är att förlora fotfästet en stund.

Att inte våga är att förlora sig själv!

Søren Aabye Kirkegaard (1813-1855)

ABSTRACT

Background and aims: 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). **Design:** Descriptive and explorative qualitative and quantitative study designs including longitudinal and cross-sectional studies. **Results:** 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: 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.

LIST OF PUBLICATIONS

- I. Ylvén, R., & Granlund, M. (2009). Identifying and building on family strength – a thematic analysis. *Infants and Young Children*, 22, 253-263.

- II. Ylvén, R., & Granlund, M. Collaborative problem-solving in the context of early Childhood Intervention. The link between problems and goals. *Scandinavian Journal of Disability Research*. Manuscript submitted.

- III. Ylvén, R., Granlund, M., & Persson, C. (2012). Problem solving in relation to resources in everyday life in families of children with disabilities – a pilot study. *International Journal of Rehabilitation Research*, 35, 102-108.

- IV. Ylvén, R., Wilder, J., & Persson, C. Family leisure activities in everyday life for families of children with profound intellectual and multiple disabilities. Manuscript

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LIST OF ABBREVIATIONS

C-YHS	Children and Youth Habilitation Services
ECI	Early Childhood Intervention
HSL	Health- and Medical Service Act
LSS	the Act Concerning Support and Service for Persons with Certain Functional Impairments
PIMD	Profound intellectual and multiple disabilities
TD	Typically developed

1 INTRODUCTION

Resources and strategies used to cope with stress related situations are important for families of children with impairments. In several articles (McCubbin, Thompson, & McCubbin, 1996; Lustig, 1999; Lin, 2000; Walsh, 2002) researchers have used different theories to explain why some families have the ability to withstand extraordinary stressors and changes by establishing new or modifying old patterns of functioning. The level of adaptation as a response to the demand for change is determined by the combination of factors constituting of internal and external resources. This thesis is an exploration of four factors; coping, problem solving, support and family activities. Families need to use problem solving to cope with stress in everyday activities, and professionals in support organizations need to know how to enhance family strengths in coping and problem solving. By combining the expertise of families and professionals in these areas the strengths of families in coping with everyday life can be enhanced.

The balance between challenges and resources in everyday life is an important part of coping and in creating healthy family functioning. From a family systems perspective this thesis focuses on how families of children with impairments manage the challenges encountered in every-day life, and how they in collaboration with professionals are supported to use their own internal resources and gain external resources. The context where the research about families' challenges and collaboration takes place is in the everyday intervention at the Swedish Child- and Youth Habilitation Services (C-YHS).

The four studies in this thesis approach have the overall aim to make an in-dept analysis of different factors relating to internal family resources associated with problem solving and coping strategies, and to external resources associated with support provided by professionals, and to activities related to healthy family functioning.

In the first study families' types of coping and their concrete coping strategies are in focus. This leads to the next study where issues discussed at planning meetings between the same families and professionals are analysed in relation to problem solving. The content of these issues are linked to activities implemented in everyday services between meetings. The results from the two first studies generated an interest in how problem solving styles are related to families' internal resources, to child characteristics and families' external resources. A pilot study aimed at guiding the

design of a forthcoming fullscale web-based study on problem solving and resources in everyday life was then implemented based on the results of the first two studies. Everyday activities and routines that are maintained are good predictors for family functioning. Leisure time is part of everyday life in most families, and for families to children with impairments it seems to be important for healthy family functioning. The last study in this thesis explores leisure activity patterns in families of children with profound intellectual and multiple disabilities.

2 BACKGROUND

Every year more than 110 000 children are born in Sweden, nearly 5 % are born with impairment. This figure is although difficult to estimate depending on how measurements are carried out. In 2011, 1 850 children were born with birth defects and chromosomal abnormalities and reported to a special register (Socialstyrelsen, 2012). In addition to this, there are impairments that cannot be observed at birth, but is discovered within a year or later, and impairments caused by accidents. For young children born with impairments as well as for other children the family is the most important proximal environment. In a family with a child with impairments the family members are affected in many ways, some of the experiences are challenging other are emotional, including both sadness and joy.

2.1 BEING A FAMILY OF A CHILD WITH AN IMPAIRMENT

Families of children with impairments are not perceived as extremely different from families of children without impairments, and the activity settings are far more similar to activities of other families in the culture than they will be different (Gallimore, 1989). During pregnancy dreams and expectations of becoming parents emerge. Sometimes the awaited child is born with impairments or chronic conditions. Realizing that the conception of the expected healthy child has to change is for many parents painful and starts a process of grieving. During a process of recovery the family rebuilds and replace earlier expectations to such more consistent with the situation (Barnett, Clements, Kaplan-Estrin & Fialka, 2003; Gaungaard & Skov, 2006; Lundström, 2007). The potential stress factor, to have a child with impairment, is followed by other stress factors related to the impairment, and factors causing disability (Guralnick, 2000). The waiting time for medical examinations, diagnosis, and the assessment process to begin is for example perceived as stressful by parents (Dellve, Samuelsson, Tallborn, Fasth & Hallberg, 2006). Families' earlier existence is challenged, because routines have to be changed, and time and energy is spent on visiting the hospital or habilitation services. Being a parent to a child with impairments also includes a lot of joy and satisfaction (Lhussier et al, 2004; Riddersporre, 2003) and over time families can eventually share stories of new hopes and rebuilt dreams for the child and the family (Barnett, et al 2003). However, certain aspects of having a child with impairments might be extremely stressful. There is no particular diagnose for the child specifically related to parental stress, but according to Dellve, et al (2006)

problems related to behaviour, and progressive impairments have a high impact on perceived stress. In addition, Jacques (2006) mention that factors such as communication difficulties is a predictor of stress. Also impairments including behaviour problems have for example high impact on everyday life for families (Kearney & Griffin, 2001; Dellve, et al, 2006; DeGrace, 2004; Myers, Mackintosh & Goin-Kochel, 2009). In families of children with challenging behavior both family life and the individual members' lives change. The family's relationships, ability to do things together, and planning for the future is affected. The behavior problems tend to have an impact on the whole family and its members may feel ambivalence regarding the family situation. In families including siblings, the sibling may sometimes be neglected and restricted to participate in activities. Siblings can feel embarrassed in front of friends, but also become more humble and increase their understanding of differences. Relatives can both be unsympathetic, and exclude the family from taking part in family gatherings because of the child's problematic behavior, or being supportive with practical help. Families can experience social isolation and restrictions in everyday experiences (Myers, et al, 2009). In the present thesis no specific medical diagnosis or a specific impairment are in focus. Within many diagnoses the in-group variance is broad, showing impairments from the most severe to the mildest.

Everyday activities and routines that are maintained are a good predictor for family functioning (Bernheimer, Gallimore & Weisner, 1990; Gallimore et al., 1989). Each family creates daily routines and a challenge for any family is to balance resources, abilities, and needs. Challenges also tend to be enhanced when a child has impairments. Routines must function and be consistent with the family's ecology and be meaningful according to the family's culture, and in providing support it is important to understand what families regard as valuable in their everyday life.

2.2 TERMINOLOGY

During the last years The Swedish National Board of Health and Welfare has developed an interdisciplinary terminology in health and social care with the aim to adapt a national technical language. In relation to disability they have published new and revised concepts. In the new terminology disability constitutes its own term and defines the limitations that occur for an individual in relation to environmental expectations and conditions. The impairments may be more or less restrictive

depending on the situation. Foremost, disabling situations refers to the absence of access or barriers in the environment. The changes imply that:

- disability is no longer synonymous with impairment, but rather denote a concept of its own
- the definition of impairment is unchanged
- the term handicap is excluded and is advised against use as synonymous to impairment as well as disability

The change in the terminology aims to clarify the distinction between what proposes an individual's limitations in ability, and what proposes problems that arise for an individual in relation to environment. Further, according to the changed terminology it is not logical to talk about individuals' with disabilities. Now, the definition of disability facilitates a univocal description of the environmental consequences for people with impairments, and allows using expressions like disabling environments or disabling processes to describe these difficulties (Swedish National Board of Health and Welfare, 2007). Although the concept handicap is excluded from the official terminology it is present in society, e.g. in relation to handicap policies, to certain institutions like Handikappcentrum [Center for Handicap], to handicap organizations, and in colloquially speech.

In this thesis the new technical language is used, and the term child with impairment is used when relating to the child. When focusing on the child with impairment in relation to environmental consequences the term disability is used. Internationally the term children with disabilities are more often used than children with impairments. Often using the International Classification of Functioning, Disability and Health (ICF), (WHO, 2001). In the title of the present thesis the term disability is used. In the included articles the term disabilities is also used more frequently adapting to international practice.

2.3 SERVICE PROVISION FOR CHILDREN AND FAMILIES

In Sweden, the state, municipalities and the county councils are jointly responsible to ensure good health, economic and social security for people with impairments. Disability policies in Sweden are based on the principle of equal rights and equality for all people in accordance with the UN Convention on the Rights of Persons with Disabilities (UN, 2006). It focuses on disability as a consequence of being disabled in

interaction with the environment. The county councils and the municipalities are according to legislations obligated to provide support and service to adults and children with impairments, and their families (HSL, 1982:763; SoL, 2001:453). The Swedish disability policy is based on a national action plan “From Patient to Citizen” (2009/10:166). Initiatives are intersectional and the responsibility for achieving disability goals lies within the relevant social area (for example labor market policy or education policy). The Ministry of Health and Social Affairs has the task of coordinating the national disability policy, and are directly accountable to the Government Handisam - The Swedish Agency for Disability Policy Co-ordination. Government and agencies are working to eliminate barriers in society and increase access, independence and self-determination for people with impairments through general support completed with customized support and service. The goal is independent living.

The Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS, 1993:387) stress the relation to the environment. The Swedish Handicap Institute (<http://www.hi.se/en/>) is a national resource center in the field of assistive devices and accessibility for people with impairments and related disabilities. It is run by central government and the interest organization the Swedish Association of Local Authorities and Regions.

The Swedish system for providing early childhood intervention is organized in similar way in the whole country, and generally the quality of service offered is considered high. Early intervention is free of charge as well as health care. It is financed by taxation. Swedish families of children with impairments are offered service and support through the C-YHS and the Child Health Organization, according to the Health and Medical Services Act (HSL). In Sweden, policy documents guiding the service and support provided to families of children with impairments by the Child and Youth Habilitation Services (C-YHS) include descriptions of a family centered approach. This implies that families are seen to be competent and aware of their needs. Part of service provision to children with impairments is provided by preschools in Sweden. Most children with impairments attend a preschool close to their home from an early age, and support for the child’s development and learning is provided through general and specific activities at the preschool. It is mandated by law (Skollag (2010:800) that children in need of special care and shall be offered a preschool placement as part of attending to their special needs.

Support and service for the children with impairments such as deafness, hearing impairment, blindness and visual impairment is provided by special clinics forced by the National Agency for Special Needs Education and Schools.

2.4 MODELS OF SERVICE PROVISION

Early childhood intervention has altered from a professional-centered intervention perspective to a family-centered intervention perspective (Turnbull, Turbiville & Turnbull, 2000). Earlier only the child was the focus of interventions, but with a family centered perspective the whole family's well-being is the concern.

Dunst, Boyd, Trivette and Hamby (2002) present four family oriented models of service provision. Each model in the framework is based on different beliefs about the family, assumptions about families' capabilities, and how the role of the professionals and the families receiving support interplay in promoting family functioning and development. The first model, *professionally centered*, view the families mostly as incapable of healthy functioning without professional interventions. The professionals are the experts determining family's needs and the families' views and opinions are neglected. Families are passive both in the intervention process and as receivers of implemented interventions. The second model, *family allied*, view families as dependent and not able to make changes in their lives. The professionals carry out prescribed recommendations and actions, while families are agents implementing interventions under guidance and tutelage of the professionals. The third model, *family focused*, view families as capable of making choices among options promoting healthy functioning. Professionals encourage and advice families to make choices and decisions, and the family's use of professionally valued interventions are monitored by professionals. Finally, the *family centered* model, view families as fully capable of making informed choices and acting on their choices. In this model it is the professionals that are the agents of families. Families have freedom to strengthen their existing skills, build capacity, and the resource and support mobilization is made by them. The first two models can be associated to professional driven intervention, whereas the family focused and the family centered model can be associated with a family driven intervention (Jung, 2007; Jung & Baird, 2003).

According to Bailey et al. (2006) support provided to the whole family unit will also benefit the child, and that support and service is effective if families experience a "good" everyday functioning. Such functioning can be supported if family centered services are provided. In a family centered approach two ways of help giving,

relational and participatory, influence how professionals behave. A relational behavior is more empowering, recognizing people's strengths, and using families' assets as a foundation for improving functioning. A participatory behavior invites families to be actively involved in identifying desired goals and actions, strengthen people's existing capacities and enhance new skills (Dunst et al, 2002). In the relational approach to help-giving support for coping is an important factor and in the participatory problem-solving is an important factor.

2.5 CHILD- AND YOUTH HABILITATION SERVICES (C-YHS)

Interventions to families of children with impairments are most often carried out in everyday life. It means that parent, the child, the siblings, other caregivers and other important persons in the child's and family's network (Björck-Åkesson & Granlund, 2003) are involved. The ecology of the support and service includes the family, the home, the preschool, the C-YHS, and the Child Health Care.

C-YHS works with coordinated activities from several competence areas in multidisciplinary, interdisciplinary or transdisciplinary approaches to intervention. Several professional groups work together at the C-YHS. The goal for habilitation services is to comprehensively promote development of the best possible functional ability and mental and physical well-being of the individual (Föreningen Svenska habiliteringschefer, 2006; Socialstyrelsens termbank, 2007). The C-YHS provides advice, support, and treatment. Through advice and support, families and relatives gain information and knowledge needed in caring for children with impairments. Families need information about the services and support at the C-YHS as well as about service and support from other providers, such as Health Care or community resources. Families also need knowledge about the child's impairment and related conditions, i.e. what the consequences of the impairment imply, in which circumstances the child can experience disabilities, and further needs. Families themselves can act on advice and support. Treatment means various targeted activities provided directly to the child with impairments by professionals at the C-YHS (Efvergren, Nordqvist, Glatz, Elgmark & Granlund, 2007). Family members may also need treatment as counseling or assistance in crisis management.

Eligible for interventions at the Child- and Youth Habilitation Services (C-YHS) are children and youth with physical, psychical (neuropsychiatric), intellectual (cognitive) impairments, hearing and/or visual impairments. The target group has gradually expanded to include children and youth with other impairments, for example

language disorders. Children and youth with multiple impairments are common. Many children with impairments have related chronically and sometimes lifelong illnesses that claim interventions from the Health- and Medical Services. The C-YHS is a complement to the Health- and Medical Services, and interventions are sometimes coordinated. Nationally the C-YHS is organized in specified geographic catchment areas related to the county councils. The responsibility for providing early childhood intervention is shared between the county councils and the municipalities, and here the preschool has an important role. The model of the Swedish C-YHS organization is unusual internationally.

The awareness that a child may have an impairment can be emerge at the child's birth, at the regularly check-ups at the Child Health Care Center, in preschool or in the context of the family. After the child is examined by a paediatrician at the hospital or a psychiatric clinic, and the child's needs of further treatment is confirmed, the paediatrician sends for a referral to the C-YHS. When a child is referred to the C-YHS, the assessment phase begins, and the medical part of the impairment often has an important role in assessing the needs of the child. As times goes on the child with impairments grows and the needs for both the child and its family changes, as well as the need for interventions. The contact between the youth with impairments and the professionals at the C-YHS may occur directly without the parents.

The C-YHS involves professionals from many disciplines; physicians, social workers, physiotherapists, occupational therapists, special educators speech- and language therapists, nurses and psychologists. If a child has multiple impairments specialists with several different types of competences are necessary to meet the child's needs. The team around the child and its family consists of the professionals needed for the planned interventions (Björck-Åkesson & Granlund, 2003). Often there is one professional in the team that is the family's contact person, and who coordinates the intervention at the C-YHS.

2.5.1 Collaboration

In the philosophy of family-centered intervention an optimal approach implies collaboration on equal conditions, as well as shared engagement and participation through the continuing intervention process (Björck-Åkesson & Granlund, 2002). The professionals have knowledge about impairments and in what way individuals can experience disability; they can support in formulating problem descriptions, have experiences and knowledge about body functions and structures, and how to promote

activity. Parents have knowledge about everyday problems and functions generally and in specific situations, family routines, about which adaptations facilitate everyday life, how to manage difficulties, and what kind of support is preferred. For optimal effect of interventions it is important that parents are active in defining and formulating the problems in focus for activities (Granlund, Björck-Åkesson & Alant, 2005). They also need to have the knowledge and skills to actively cope with problems that are possible to affect.

The need for interventions for the child and the family varies over time and the collaboration is experienced as meaningful if the activities correspond with the phase in the families' life-cycle (Adolfsson & Resare, 2000). Parents have substantial needs for information, advices and support, the amount and intensity are partly related to type and severity of the children's impairments. This means that the need for support is related to many factors whereof the child's impairment constitutes only one (Granlund & Roll-Pettersson, 2001). Trying to meet both needs and rights of children and parents, is a complex task for professionals. Carlhed, Björck-Åkesson and Granlund (2003) stated that there is a paradox between a rights perspective and a need perspective. Some parents want a more flexible intervention, and feel disappointed when professionals disagree with their preferences (rights perspective). At the same time the parents may emphasize a need for relationship and security (need perspective). Service providers' have to use their professional competence as a benchmark in collaboration with parents when deciding what needs to meet, and how to balance the demands for safeness and freedom of choice (Carlhed, 1998; Carlhed, Björck-Åkesson & Granlund, 2003). The choice of perspective in the intervention process determines where to focus the activities. A developmental perspective focuses on the child's development, whereas a functional perspective focuses problems arising in everyday life (Björck-Åkesson, Granlund, & Simeonsson, 2000). In the intervention process both perspectives are needed. When activities aim to accomplish a well-functioning everyday life the probability increases that the collaboration between parents and professionals also will focus on the child's development (Carlhed, Björck-Åkesson & Granlund, 2003). Central themes in collaborative problem solving are planning meetings and individual plans.

2.5.2 Planning meetings and individual plans

According to the Health- and Medical Service Act (HSL, 1982:763) the responsible authority is obligated to establish individual plans regularly. The Act Concerning

Support and Service to Persons with Certain Functional Impairments (LSS, 1993:387) on the other hand demand that the user him-/herself takes the initiative to request for an individual plan. In relation to LSS the parent to a child with impairment can take the initiative to establish an individual plan, but only if the child earlier have received activities according to LSS. Individual plans according to the HSL are established by the Child and Youth Habilitation Services (C-YHS) in the county councils, in distinction to individual plans according to LSS, which are under the responsibility of Social Services in the municipality. These two legislations have in common that the individual plans are established in consultation with the user/parent/child. Many times the plans are developed in planning meetings.

The planning meeting is an approach and a model for planning to secure participation, quality, and coordination. It implies that families and teams plan together, work for, and evaluate agreed goals.

The individual plan is an agreement between the C-YHS and the family about how to collaborate. The purpose of the individual plan is; to make families, and children/youth involved in planning and implementation of intervention activities; to give families impact over the design of the intervention activities; to make clear agreements about how to work together to achieve goals; to strengthen families own resources, knowledge and reduce the need for support. Thus a central feature of this process is collaborative problem solving.

The individual plan is based on the child's/youth's/families' needs, goals, and interests, and contains activities that are based on their main priorities to fulfill needs and attain goals. The inventory of needs builds on a collective assessment of the children/youths health, daily activities, participation, and environment to detect areas or situations the family or family members experience major limitations, and where a change is desired. It is within those prioritized areas of needs that goals and individual plans develop. Priorities and wishes are the child's/families' own, but the long-term and short-term goals and individual plans have to be designed in consultation with professionals. Based on the goals, activities are planned, and decision about who is conveniently responsible for what, and in which order activities should be implemented are made.

The individual plan is most often followed-up once a year and evaluated according to goal achievement. The plan may have to be revised, or the process may starts allover with a new assessment, or if no further needs remain the contract is cancelled.

2.6 OUTCOMES OF EARLY INTERVENTION

Interventions at the C-YHS are most often focused at the family member with impairments in terms opportunities to development and to lead an independent and eventful life in community with others. Family's needs are always considered and the family's participation in the intervention process is strengthened in various ways with the full participation as a goal. The collaboration with families and their informal network is made from a holistic perspective focusing on health factors. A goal for C-YHS is a good and secure habilitation and that the child with impairment and families can participate in society based on their own choices. Outcomes from activities provided by C-YHS shall contribute to a well-functioning everyday life for the member with impairments and the family, including siblings. Participation in daily activities at home, in preschool, and in leisure time is important. Through the concept of family centeredness the family have an active part in intervention. Thus another outcome is that the family and other persons in the local environment have the knowledge and competence that is needed to support the member with impairments. A long-term goal is therefore to strengthen the family's own resources and reduce the dependency on the support from C-YHS. As mention earlier the family centered model of intervention is family driven and view families as fully capable of making informed choices and acting on their choices. The role of the professionals is merely as agents of families. It means that families strengthen their existing skills, build capacity and mobilize the resource and support themselves.

How family centered the support from the C-YHS is perceived by families can be evaluated using the questionnaire Measure of Processes of Care (MPOC) (King, Rosenbaum & King, 1998) which is used in most county councils in Sweden. The result of the questionnaire provides a perception about how families perceive the collaboration and their expectations on C-YHS. The questions in the survey are related to parental impact, information, coordination, encountering, and knowledge. Several county councils report the lowest scores in the part of MPOC concerning parents learning and knowledge, skills that are strongly related to parents coping. Examples of questions in this part are if the C-YHS have; provided parents with possibilities to targeted learning opportunities about the child's impairment, what it means and what parents can do to facilitate in everyday life; offered other relatives, such as mother- and grandparents, with possibilities to have targeted learning opportunities about the child's impairments, what it means and what they can do to facilitate in everyday life; have

offered targeted learning opportunities about how to work out ordinary everyday problems, e.g. sleep, food, toilet training, behavior.

Questions about alternative methods to measure the outcome of intervention on a family level have been raised (Granat, 2004; Bailey et al, 2006). Bailey et al, (2006) argue that effectiveness of activities provided by early intervention services can be inferred from how families describe their situation. Thus, outcomes of family support need alternative measurements, not focusing on the families' satisfaction of intervention but on outcomes at a family level. Those can be expressed in terms of increased knowledge about; the child's impairment and related disabilities; activities provided by C-YHS and other authorities; the child's needs in daily care and child participation in family activities (Bailey, 2001; Summers et al., 2005; Bailey et al, 2006). It can also be expressed as outcomes in terms of the family's experience of increased coping, being in control and participation in the intervention process.

3 THEORY

The concept system refers to a “complex of interaction elements” (von Bertalanffy, 1969:55). Systems approaches that are related to understanding human behavioral-developmental variability and how parts within a system interact with each other, is dynamic systems theory and general systems theory. Both are used to describe changes within human systems. Dynamic systems theory attempts to explain sudden term changes in systems that are not hierarchically constructed and sensitive to initial conditions. General systems theory attempt to explain changes that occurs over longer periods in hierarchically constructed systems with self-regulating functions (Wachs, 2000; Bornman & Granlund, 2007).

Applying general systems theory to research about families of children with impairments and the support they receive from C-YHS is useful. Systems theory applies a broader perspective on early intervention because it focuses on the interdependency between both biological and contextual factors, where the context of the child with impairments becomes important. A systems perspective provides a framework that also focuses on different levels of reality. One part of the family cannot be fully understood on its own but, rather, must be considered in relation to the whole system. When intervention is focused only on the child it may not benefit the whole family (Bornman & Granlund, 2007; Epstein et al., 2002).

Ecological systems theory (with its roots in general systems theory) and family systems theory (with its roots in dynamic systems theory) are theoretical constructions that provide a structure for policy and intervention. These theories are also important in understanding the way of thinking in the activity settings that are the subject for investigation in the present thesis.

3.1 ECOLOGICAL SYSTEMS THEORY

Families do not exist in a vacuum. From an ecologic systems theory perspective the family is seen as a component or one system in a larger system, containing a network of other systems in the surrounding society (Hanson & Lynch, 2004). Ecological systems theory is a theoretical construction useful in explaining human development and how the development is affected by multiple interrelated influences.

The Ecology of Human Development perspective (Bronfenbrenner, 1979) places the family in a broader context, and shows the relations between the developing individual and the context. For children the family is the primary

microsystem. Another microsystem for most young Swedish children is the preschool. Families' relation to other microsystems, where both families and children interact is placed in the mesosystem (home-preschool, home-C-YHS). The exosystem consists of activity settings influencing children without an active participation from the child (families' social network, neighborhoods, parents working places). Activities in the exosystem are in turn influenced by the children. The macrosystem contains social and cultural beliefs and values that tie a society together, and affect the lower levels in the ecocultural system (e.g. child-rearing patterns, attitudes to disabilities, economy, philosophy, and policy, e.g. inclusion).

In the present thesis all systems levels are considered. The C-YHS are governed by laws, policies and finances (macrosystem level), this affects for example how the C-YHS are organized (exosystem level) and possible support to families (micro level). Most focus is on the meso- and microsystem level. The mesosystem level is important because it contains relations and contacts between the members involved in the context of the family. Factors affecting the mesosystem negatively are when there are few contacts or no contact between microsystems, or if there are conflicts between the members involved. Examples are if the family and the professionals do not have the same opinion of what is the best for the child with impairments, or if there are disagreements regarding the goal with a certain intervention. This could be a consequence of different values between the microsystems. Sometimes time and engagement is needed to establish a well-functioning mesosystem. A strong social network characterized by many contacts, continuity and quality promotes positive development of the family and its members. In positive cases the whole system (mesosystem) is bigger than the sum of its parts (microsystems) (Garbarino & Abramowitz, 1992). Three different microsystems are in focus in the present thesis, foremost the families' microsystem at C-YHS, and the home and the preschool.

3.2 FAMILY SYSTEMS THEORY

Families are dynamic systems, and according to system theoretic thinking, built on a number of assumptions. First, the different parts in the system are connected to each other, i.e. the family members are linked together in an integrated system. Secondly, the family as a system could only be understood as a unit and not from individual parts. Thirdly, the family as a system influences and are influenced by the environment, and finally, the family's system does not exist as a physical reality, it is more like an understanding of a shared organization and experience of being a family (Hanson &

Lynch, 2004). Families can be characterised as more or less open systems depending on how sensitive families are to influences from outside. Families' adaptation to outside or inside influences is a striving to reach balance, homeostasis. A family of a child with impairments might need to adapt to the new responsibility of having the child both internally and externally, e.g. by changing routines, working time or life-style. The family's system may also be characterised by their relation to change. Some families have difficulties to change because of internal control needs and strict rules, whereas other families are too flexible to change, which can threaten the stability in the family (chaos). The willingness to change varies depending on the demands on the family. When demands and stress are high on the family the perception of congruence is very important (Friedemann, 1995) because it affects family health. Congruence is reached when there is a balance between stability, control, development and dynamics in relation to changing family situations. Friedemann adopts a process directed perspective, where the same stressor seems to cause different effects on family members depending on their function in the general family process. In this context coping is related to how the family manages change and adapts to new situations and reaches a balance, both as parts, i.e. individual family members, and as a whole.

3.3 FAMILY HEALTH AND FAMILY FUNCTIONING

What constitutes family health is depending on the perspective used (Friedman, 2003). From a systems theory perspective the assumption is that family health is more than the health of each individual family member. Families that function well and experience health manage to find balance between growth/change and stability/equilibrium in relation to the exchange between the family as a system and its environment (Wright & Leahey, 2009). A holistic perspective on family health grounded in systems thinking constitutes that family health: "is a dynamic changing state of well-being, which includes the biological, psychological, spiritual, sociological, and cultural factors of individual members and the whole family system." (Harmon Hanson, Gedaly-Duff & Rowe Kaakinen, 2005:7). Further "family health is more than the absence of disease in an individual family member or the absence of dysfunction in family dynamics" (Bomar, 2005:244). Family health is associated with families' adaptability and family functioning (McCubbin & Patterson, 1983). Family health in terms of adaptability is commonly used in perspectives on stress, explaining families' responses to stressful circumstances as processes where families use multiple coping strategies (Clawson, 1996). 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 (David, 1978).” Family functioning can be understood as a process of dynamic engagement between developing family members and the environment over the family’s life course (Denham, 2003). Together family members form a unit of interdependent members who interact with each other sharing commitment, responsibilities, resources, values, and goals, over time. Family functioning embraces aspects of instrumental functioning (i.e. routine activities of daily living) and expressive functioning (i.e. communication, problem solving, roles, beliefs, alliances and power). These two aspects are interacting and if families experience problems within instrumental functioning, expressive functioning is most often affected (Wright & Leahey, 2009).

In the present thesis different perspectives have influenced the view on family health pointing to that it is a complex phenomenon that can be grounded in different disciplines. The complexity of family functioning is particularly vulnerable when the family and its members encounter health threats. In living an optimal and satisfying everyday life families of children with impairments need resources. Some of them are internal, like problem solving skills, positive problem-solving styles, coping strategies, and competence as a parent/family, while others resources are external like a functioning informal and formal social network.

3.3.1 Problem solving

Everyday life is full of challenges and uncertainty about what will happen tomorrow or the next day. Problem solving is important to manage unpredictable occurrences. Problems can appear both within and outside the family and becomes more obvious when the family is unable to solve them. Tallman (1993) divides problems in three parameters, each parameter describes essential parts of a problem; the source of the problem, necessary requirements to cope with the task, and control over the solution of the problem. When the source of the problem is identified, initiates the gathering of information about the problem. The family’s ability to communicate with each other is very important for an effective problem solving. The occurrence of communication difficulties within the family may become an obstacle. There are necessary steps or rules for problem solving; these may be process-related, analytical, or regulatory, or a combination of these. Many problem families encounter are rule governed, these rules are sometimes not explicit but must be discovered during the problem solving process. This is facilitated if there is openness, flexibility and tolerance in the family.

Further, a distinction can be made between problems there are separating and problems there are unifying. Problems that are unifying demands activities from all family members to be solved, e.g. when to restore the family's moral or reorganize the family when one family member dies. The problems complexity, i.e. the amount of parts and the interaction between them, affects how much information that needs to be processed to reach a solution of the problem. Tallman (1993) mention three types of problems; if the problem have one right solution (control); if the problem require strategies (conflict of interest); and problems solved by gambling (risk taking) (Tallman, 1993). Many problems in everyday life demands strategies to be solved.

The family and the child with impairment benefit when parents have a repertoire of problem solving skills. Problem solving is seen as a process and are expressed in problemorientation and problem solving-styles (D'Zurilla, Nezu, & Mayen-Olivares, 2002; D'Zurilla, 2011). Problem orientation can be positive or negative. Problem orientation is the motivational component facilitating or inhibiting the individual's effort to solve problems, depending on if the attitude to solve problems are positive or negative (Elliot, Shewchuk, & Richards, 2001; Shewshuk, Johnson, & Elliot, 2000; D'Zurilla, 2011). Having a positive problem orientation (PPO) means that problems are viewed in a positive light and there is an optimistic attitude towards own abilities to find and implement solutions. Problems are seen as challenges rather than threats. Having a negative problemorientation (NPO) means to have a lack of motivation towards problem solving, emotional negative moods and pessimism affects the problem solving. Specific problems related to stressful situations in everyday life can have a strong impact on family functioning. How family members perceive problems is important and affects the family's problem orientation. Problem solving skills and a positive problem orientation is viewed as strength enhancing effective everyday functioning and positive well-being in families (D'Zurilla, et al, 2002). Families with a positive problem orientation tend to handle the problem solving process more easily when a challenge is approaching. Professionals can support families in developing good problem solving skills and guide families through the problem solving process. In a process of collaborative problem solving (Karlsson, Björck-Åkesson, Granlund, 2008) families and professionals can work together using their specific knowledge and expertise to solve everyday problems or challenges for the family.

3.3.2 Coping

Coping is a concept describing both responses and resources to external or internal stressors. In stressful situations coping is used as a response to manage a stressor. Responses can be problem focused or emotional focused depending on how the stressor/the stressful situation is perceived (Folkman, 1997). According to Almborg et al (1997) problem focused coping is associated with active coping, whereas emotional focused coping is associated with passive coping. Emotional focused coping responses may be perceived as passive, e.g. escape-avoidance or distancing, but in certain situations such responses could be the most effective if the situation is interpreted as overwhelming (Folkman & Moskowitz, 2000). The coping process involves ongoing efforts both in thoughts and actions to cope with demands and stressful situations. Coping strategies are contextual, and to be effective, these alter depending on the characteristics of the situations and over time (Lazarus, 1993). In situations perceived as possible to change, problem-focused coping is effective, but in relation to situations perceived as impossible to change, it may be necessary to cope emotionally and use emotion-focused coping (Azar & Solomon, 2001; Cimete, 2002; Steele & Fitch, 1996).

How families cope in stressful periods is an important indicator for how they master their life situation (Walsh, 2002). Families' adaptability is especially facilitated if positive coping strategies are applied. Folkman (1997) distinguished four types of coping, and those types of coping are used to solve problems, finding meaning and reduce stress. In the process of coping the meaning of a situation may be changed and allow experiences of positive emotions and well-being which gives a time-out from the ongoing stress (Folkman & Moskowitz, 2000).

The ability to cope with the challenges of becoming parents to a child with impairments is individual and varies over time. In a family centered intervention approach families' strengths and ways to cope with stress are important to identify, and to provide support necessary to strengthen family functioning (Dunst, Trivette & Deal, 1994; Dunst, Trivette & Hamby, 2007). Families concerns and worries are important sources of what families' perceive as stressful. To detect those and discuss them in planning meetings may help families to adjust their coping strategies. Professionals can provide support through changing the perception of stress factors (Mellin et al, 2004). Folkman and Moskowitz (2000) suggest that positive appraisal of the demands of child caregiving may be particularly important in helping parents to sustain these efforts over long periods of time. Some studies (Lin, 2000; Grant & Whittell, 2000;

Folkman, 1997; Folkman & Moskowitz, 2000) show that families use a number of different coping strategies to manage the complex reality it implies to have a child with impairment. Encouragement of families coping strategies from professionals is a prominent part in the coping process (Johansson & Ringsberg, 2004; Pelchat & Lefebvre, 2004; Puotiniemi, Kyngäs, & Nikkonen, 2002).

In families encountering stressors from both within and from outside the family system the individual family members have their personal coping strategies, but sometimes stressors have to be coped with at a collective level (Antonovsky, 1998). An example is the experiences of a family with a newborn child with impairments and how this may be perceived as a challenge within the family. Further, a family system perspective can explain how reactions from the environment outside the family unit may be stressful for the family, who has to cope collectively.

Generally, families raising children with impairments adapt well to the challenges, although positive experiences seem to go hand-in-hand with stressful experiences. Most families seem to go from stress reducing coping strategies to cognitive and problem solving strategies (Grant & Whittell, 2000). One of the most potent factors in coping for families is to experience positive situations and moments when they enjoy life together. Leisure activities can be part of such situations and happy moments together.

3.3.3 Family leisure activities

The value of family leisure experiences has been widely acknowledge and that family leisure is associated with several family strength such as; family cohesion, adaptability, and overall family functioning (Freeman & Zabriskie, 2003; Smith, Freeman & Zabriskie, 2004); satisfaction with life (Zabriskie & McCormick, 2003); overall quality of family life (Mactavish & Schleien, 1998); and positive interaction between family members (Shaw & Dawson, 2001). Participating together in positive health promoting daily life activities is important for families. Families are committed to this aspect of family life and attach a strong sense of meaningfulness to family participation. Family leisure promotes positive interaction between the members in the family, both between parents and children and between siblings, and maintains a “sense of family.” (Shaw & Dawson, 2001). Factors contributing to healthy family functioning is important especially for families of children with impairments (Zabriskie & McCormick, 2001; Dodd, Zabriske, Widmer & Eggett, 2009; Townsend & Zabriskie, 2010), because these families may experience more stress than normally in

everyday life (Hornberger, Zabriskie, & Freeman, 2010). Mactavish and Schleien (1998), show that family leisure was important for the whole family as well as their child with developmental impairments, because being together in leisure activities offers an accepting and social situation for their child.

Zabriskie and McCormick (2001) developed a model founded in family systems theory for exploring family leisure activities, and summarize that “families are goal directed, self-correcting, dynamic, interconnected systems that both affect and are affected by their environment and by qualities within the family itself.” (Zabriskie & McCormick, 2001:281). Further, they add three dimensions; family cohesion (i.e., togetherness); family adaptability (i.e., the ability to cope with change), and family communication from the Circumplex model of marital and family (Olson, 1986 in Zabriskie & McCormick, 2001) which is also based on family systems theory. Using a family systems framework enrich the understanding of how family leisure influences family functioning (Agate, Zabriskie, & Eggett, 2007). Zabriskie and McCormick (2001) distinguished between two patterns of family leisure. *Core* activities are informal and require little planning, examples are playing board games, watching television or videos, playing, eating dinner. *Balance* activities provide novel experiences and are generally less common; examples are special events, outdoor recreation, going for trips.

4 THE AIM

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 everyday life. This is examined in the context of the support provided by the Child and Youth Habilitation Services (C-YHS). Two types of family resources, internal and external are considered. Internal resources concern coping strategies and problem solving within the family and external resources concern support provided by professionals at the Child and Youth Habilitation Services (C-YHS).

In study **I** families' types of coping and the concrete coping strategies were in focus. This was investigated in planning meetings where families and professionals took part in collaboration. In a family centered activity family support is expected therefore it was interesting to explore if and how professionals encouraged the families' coping strategies.

The following research questions were addressed:

- Can the four types of positive coping described by Folkman (1997) be identified in conversations between families and professionals in planning meetings and in interviews with families?
- Are the types of coping related to certain potential stressors?
- What are the interaction characteristics of the coping process?
- Do families perceive that professionals encourage them in situations where coping strategies are needed?

In the second study (Study **II**) the processes and the content of issues discussed at planning meetings between families and professionals at the C-YHS were studied with problem solving as a special focus. If and how was the content of issues discussed related to activities implemented in the everyday services between meetings was investigated.

The following research questions were addressed:

- On what content are the processes focused?
- What activities are initiated based on problems identified at planning meetings?
- What is the correspondence between plans developed at meetings and activities implemented in everyday services?

Study **III**, is a pilot feasibility study intended to provide a background and design for a forthcoming fullscale web-based study about problem solving in relation to everyday life of families of children with impairments. Problem solving consists of problem orientation (positive and negative), and different problem solving styles; rational problem solving (RPS); impulsivity/carelessness style (IC); and avoidance style (AV). The forthcoming study will be designed to examine how problem solving styles are related to families' internal resources, i.e. coping, to family competence, to child characteristics, and to external resources, such as informal network, support from C-YHS, and individual habilitation plans.

The following research questions were addressed:

- How well does the quality of collected data correspond conceptually and in measurement terms to basic criteria for the planned analyses in the future study?
- What possible strengths and weaknesses could be identified related to the planned web-based procedures for recruitment of participants and data collection?

Finally, in Study **IV** families leisure activities were in focus. Families of children with impairments strive to find a balance between challenges and resources in everyday life. Family leisure activities may be conceptualized as a good family outcome of coping and problem solving. Being involved in leisure activities seems to be essential for families, especially in activities where all family members are present. In the study leisure activity patterns in families of children with profound intellectual and multiple disabilities were explored using a theoretical framework supporting healthy family functioning.

The following research questions were addressed:

- To what extent are families of children with profound intellectual and multiple disabilities involved in core and balance leisure activities? In what way is the extent of family involvement associated with certain family characteristics?
- Does family involvement in core and balance leisure activities differ, compared with families of children with typical development and if so, in what ways?

5 METHOD

Table 1. Overview of research with specific aims, design, participants, data collection and analysis

Study	I	II	III	IV
Aim	To investigate professionals' encouragement of parental coping strategies, with the help of observations and interviews	To compare the content of issues discussed at the planning meetings, with the activities implemented in everyday services provided by the Child and Youth Habilitation Service (C-YHS) between meetings	To examine the design of a future study focusing on problem solving in families of children with disabilities, and how different problem solving styles are related to internal and external resources	To explore leisure activities patterns in families of children with profound intellectual and multiple disabilities (PIMD) for activities where all family members in the household are involved
Design	Theory-driven, longitudinal, observational, and descriptive	Longitudinal qualitative multiple case study design	An explorative pilot study with inspiration from the two earlier studies (Study I-II)	An explorative cross-sectional study design
Participants	Families and their personal team at C-YHS ($n=5$)	Study sample, see study I	Families of children with disabilities ($n=13$)	Families of children with PIMD ($n=53$), families of children with TD ($n=103$)
Data-collection	Videotaped planning meetings and interviews	Videotaped planning meetings Interviews Memory-notes Informal information	Survey consisting of questionnaires	Questionnaire
Analysis	Deductive theoretical thematic analysis	Conventional content analysis	Descriptive statistics analysis	Mann Whitney u-test, Chi2

5.1 DESIGN

The designs of the first two studies were created to study intervention content and processes in interventions. Thus longitudinal qualitative designs were chosen. In order to generalise the results from study one and two a pilot study with a quantitative design was performed. It aimed to test methods for studying the relationship between aspects of problem solving styles and internal and external family resources. The last study had a quantitative cross-sectional design aimed to explore family leisure activities, a concept that theoretically and empirically is associated with family well-functioning.

5.2 PARTICIPANTS

Two of the studies (**I** and **II**) is based on the same sample. For participating in the studies some criteria had to be fulfilled. The families and the child had to be new cases for the C-YHS. Furthermore, it was desirable that the children had impairments with additional conditions which required attention and support from several professional groups. Five families newly enrolled in intervention programs at the C-YHS in different county councils in the central parts of Sweden gave their consent to participate. The five families had one child each with a disability (boys $n=3$ and girls $n=2$), and two or three older children without impairments. When the data collection started, the ages of the children were 10 months ($n=1$), 1 year ($n=2$), 2 years ($n=1$), and 5 years ($n=1$). The types of diagnoses were chromosomal abnormalities, spina bifida, metabolic disorder, and birth-related brain injuries. Related disabilities were motor impairment, epilepsy, developmental delays, speech and communication problems, food problems, hearing impairment, and autism. The professional teams at the C-YHS consisted of speech pathologists, pediatricians, physiotherapists, social workers, special educators, occupational therapists, pediatric nurse, and others. In the team around the families the constellation of professionals could vary over time depending on what interventions was needed for the child and their families.

Participants in the pilot study (**III**) were families of children with impairments. The inclusion criteria for participating in the planned major study were that the families should be enrolled in the C-YHS and having a child between 0 and 12 years of age. The age criterion was decided on the assumptions that intervention activities are usually most intense in the first years of life, children older than 12 years were excluded. In the pilot study 13 families of children with impairments participated.

Twelve of these families had at least one more child. The children had different diagnoses and most of the children had multiple impairments. The majority had severe physical impairments, chronically health problems, severe impairment in social skills, behavior disorder, moderate limitations in understanding communication, severe limitations in communicating, moderate vision impairment, and moderate cognitive delay. For six of the families the contacts with the C-YHS occurred more than once a month. Four to five professionals at the C-YHS were included in the team around the family.

In the last study (IV) two samples were included. The inclusion criteria for the first group were families who had a child, initially aged 0-20 years, with profound intellectual and multiple disabilities (PIMD) who made use of the right to personal assistance according to the Swedish act of Law LSS/LASS (SFS 1993:387; SFS 1993:389). The first sample consisted of 60 families of children with PIMD, 5-20 years of age. The types of diagnoses were chromosomal abnormalities, cerebral palsy, hydrocephalus, birth-related brain injuries, and other rare diagnoses. Related disabilities were motor impairment, epilepsy, developmental delays, visual impairment, speech and communication problems, food problems, hearing impairment, and autism. The inclusion criteria of the second group were families of children with typical development (TD) with a child aged 5-10 years. The second sample consisted of 107 families of children with TD 5-10 years of age.

5.3 DATA COLLECTION AND PROCEDURE

For two of the studies (I and II) data were collected in conjunction of large longitudinal project *Dimensions in intervention processes – collaboration between families and professionals in Early Intervention for children with disabilities* (DIIS) (ISB9-266/06). For the two studies (I and II) a number of methods of gathering data were used. Data were collected from five families of children with impairments and their teams, followed from fall 2002 to spring 2005, and during a time period of at least 32 months. Data consisted of observations of videotaped planning meetings ($n=11$) between professionals and families of children with impairments at five different C-YHS. Data from interviews ($n=7$) with the families was also included in the study, conducted between the planning meetings by another member of the research group. The planning meetings involved the family and the professionals and were held approximately twice a year. Sometimes, the child's personal assistant or special

educator at the preschool participated. The planning meetings were videotaped by team members. The videotapes and the interviews were both transcribed verbatim. Both mothers and fathers in the five families participated in the study mostly together in the planning meetings, sometimes together in the interviews. Individual interviews were conducted with both mothers and fathers. In a few planning meetings, the mother was alone, but there was no planning meeting with only the father.

The videotaped planning meetings and the interviews from the first study (I) was used in the next study (II). From study I transcribed data from 73 sequences out of 164 containing data related to identifying, discussing, and solving problems in the planning meetings and interviews was chosen. For study II this data was extended with memory notes from professionals at the C-YHS and families, and informal information from the professionals. Filled in memory-notes with pre-printed open-ended questions were sent in once a month by participating families and professionals separately from occasions when they had been in contact with each other, through appointments or telephone calls between planning meetings. Each contact generated one memory note. Informal information from professionals was audio taped using Dictaphones and consisted of short narratives of chats with family members, with colleagues, and other professionals involved in the case. The total data consisted of memory-notes ($n=500$), informal information ($n=231$), transcribed data from planning meetings ($n=10$) and interviews ($n=7$).

A survey was constructed for study III based on questionnaires including background data concerning the families and the child's impairments, their contacts with the C-YHS, and together with validated instruments measuring coping; problem orientation; family networks; families perception of the individual plan at the C-YHS; and family outcome of intervention. The questionnaires had mostly close-ended questions and a few open-ended questions. The survey was tested in collaboration with two families of children with impairments, using the 'think aloud' technique. The families reported that the survey was time consuming and took approximately 40 minutes to fill in due to the large number of questions. Further, they perceived several questions to be almost identical (e.g. in the SPSI-R). In the pilot study problems with the web-based survey occurred and contact was established with an association Jämlikhet, Assistans & Gemenskap (JAG) [Equality, Assistance & Inclusion] to recruit participants. The web-survey was printed out as a paper-and-pen survey. Personal at the association

distributed 50 surveys to their members matching the criteria for the major planned study and 13 was returned anonymous.

Finally, in study **IV** data was collected in a larger project *Children with multiple disabilities: Childrens' participation in family activities* [Barn med betydnande funktionshinder: Barns delaktighet i familjeaktiviteter] (Dnr. 2010/016). The participating families of children with PIMD were recruited by contact with three national disability organizations in Sweden; Equality, Assistance and Inclusion (JAG), The Swedish National Association for Disabled Children and Young People (RBU), The Swedish National Association for Persons with Intellectual Disability (FUB). Data was collected using the questionnaire Child-PFA (Participation in Family Activities). In one of the organizations the members received a web-version of the Child-PFA. Members of the other organizations as well as the families of children with TD received a paper-version. Reminders were sent twice to families who received the web-version, but no reminders were sent to families receiving the paper-version in the families of children with PIMD. Three hundred families of children with PIMD fulfilled the inclusion criteria and received a questionnaire, 65 questionnaires were returned. Five families were excluded resulting in 60 families. Analysis of the reasons why families chose not to participate was not possible to do. Families of children with TD were recruited by convenience through snow ball sampling. One hundred and forty-five questionnaires were distributed and 107 were returned.

5.4 INSTRUMENTS

In two of the studies (**III** and **IV**) data was collected using questionnaires. Based on the two earlier studies (**I** and **II**) a battery of questionnaires and instruments about internal resources and external resources was compiled in a survey used in study **III**.

Family's socio demographic characteristics

a) Demographic variables were gathered by questions about family constellation, education, work and residential/housing standard. No personal data was obtained, and all participants were anonymous.

b) Questions about the Child and Youth Habilitation Service (C-YHS) the families' belonged to (not geographic area) were asked, for example frequency in contacts, accessibility of phone calls and meetings, professional occupations represented at the C-YHS.

c) To assess the child's impairment the Swedish version of the **Abilities Index** was used (Simeonsson & Bailey, 1984; Simeonsson, Roll-Pettersson, & Granlund, 1990/2nd revision 1992 (SFO); Roll-Pettersson & Granlund, 2001).

Family's competency, and family's perception of the activities provided from Child and Youth Habilitation Services (C-YHS). Data were gathered using following instruments; **"Family Outcome Survey" (FOS)** (Bailey, Hebbeler & Bruder, 2006) measure outcome of intervention on a family level and can describe competence in the family, for example knowledge about the child's condition; the child's development and how to promote development; knowledge about support for the child and the family. Family Outcome Survey was translated to Swedish with permission from the constructor (Ylvén, 2009).

"Goodness-of-fit" (Albin et al, 1996; Wilder, 2004, Swedish version). Goodness-of-fit measures the family's perception about how well the individual plan, developed together with professionals at the C-YHS, fits into the family and its everyday life. The individual plan constitutes of the goals the parents have for their child and the activities the family and the professional have decided on. A Swedish translation was made by Wilder (2004), and a study by Folkö (2007) reports good validity.

Familyfactors. Data were gathered using following instruments;

"Ways of Coping Questionnaire" (Folkman & Lazarus, 1988) WCQ-S (Ahlström, 2003, Swedish version). Ways of Coping Questionnaire (WCQ) is a self reporting instrument to assess coping behaviour. WCQ is internationally well-known and translated into a number of languages. The Swedish version (WCQ-S) was translated by Ahlström (2003) and tested in Sweden (Ahlström & Wenneberg, 2002; Lundqvist & Ahlström, 2006; Gustafsson, Edvardsson & Ahlström, 2006). The Swedish version consists of 45 items and has shown satisfactory psychometric properties in clinical studies with acceptable to good results concerning internal consistency, test-retest reliability and concurrent validity.

"Social Problem Solving Inventory – Revised" (SPSI-R) (D'Zurilla, Nezu, & Mayen-Olivares © 2002, MHS. Inc.). SPSI-R consists of 52 items and is a self reporting instrument to assess problem solving within everyday life. SPSI-R has been translated to a great number of languages and are used internationally in research and

clinical activities. In Study III the Swedish version of SPSI-R was used (Swedish SPSI-R:L). The SPSI-R has been evaluated concerning psychometric properties in diverse populations and show strong internal consistency and stability over time, as well as strong structural, predictive, convergent, concurrent and diskriminant validity. The Swedish version that was translated by expertgroups related to Multi Health Systems Inc (MHS) Psychological Assessments and Services has not been used earlier used Sweden.

“The eco-cultural family interview” (EFI) (Weisner et al, 1997) is a semi-structured interview with open-ended questions assessing accommodations in everyday life for families of children with disabilities. The interview covers ten domains: *family subsistence base, use of services, home/neighborhood, safety and convenience, domestic workload, childcare tasks, child peer groups, marital roles, instrumental/emotional support, father/spouse role and sources of information*. The eco-cultural family interview has been translated to Swedish (Granlund, Sandell, & Björck-Åkesson, 1997). In Study III only one domain, the *instrumental/emotional support*, from the entire instrument was used and followed the structure in the Eco-cultural family interview questionnaire (Ecocultural Scale Project, 1997) with close-ended questions. The response options were from 1=not at all to 4=very strong, and yes/no.

The data used in study IV was based on a questionnaire, Child-PFA (Participation in Family Activities). The questionnaire was developed through a review of the literature, expert review, and pilot testing with families of children with PIMD (Axelsson & Wilder in press). In the final version of Child-PFA, part A included background questions about the child and the family, for example child’s ability level and the family’s structure and socioeconomic status (SES). To measure child ability level the Abilities Index (Bailey et al., 1993) was used. The Abilities Index measures functional abilities and communicative complexity in children with PIMD. High ratings indicate a high degree of difficulties/health problems. Part B of the questionnaire included 56 listed family activities with questions about occurrence of activities, attendance of family members, child’s engagement, help from personal assistant, and the use of assistive devices. Activities were organized in six domains: Indoors activities, Mealtimes, Routines, Outdoor activities, Organized activities, Outings and Vacation and holiday cottage. The questionnaires were modified depending on if it was sent to families of children with PIMD or TD. This resulted in that 53 of the activities were the

same in both groups. The Child-PFA, has been used in a few studies (Axelsson & Wilder, in press; Axelsson, Granlund & Wilder, accepted), and psychometric evaluations have not been reported apart from Cronbach's alphas (0.826-0.844).

5.5 DATA ANALYSIS

In the first study (I) data was analysed deductively. Inspired by the *theoretic thematic analysis* model (Hayes, 1997) themes were determined in advance emanating from Folkman's (1997) theoretical concepts of four types of positive coping. Folkman (1997) distinguished four types of coping; positive reappraisal (PA), goal-directed problem-focused coping (GDPF), spiritual beliefs and practices (SBP), and positive events (PE). Three themes representing each of the four types of positive coping were created, that is, 12 themes. The creation of the themes was based on a literature review including research articles about coping (Ylvén et al., 2006). The themes represent 12 different coping *strategies*. The first type of coping Positive appraisal includes the three strategies; minimizing, reframing, and adaptation. The second type of coping Goal-directed problem-focused includes the three strategies; searching for information, problem solving, and goal-setting/decisions towards goals. The third type of coping Spiritual beliefs and practices includes the three strategies; values, optimism, and existential questions. The last type of coping Positive events includes the three strategies; humor, meaningful activities, and represent good memories. In the analysis data were selectively sorted according to each theme. The framework for analyzing coping strategies was used for the transcribed videotapes as well as the interviews. In the first phase of the analysis, the transcribed data were read and reread. In the second phase, the reading of the data was aimed at discovering sequences that could apply to the four types of positive coping. The example below shows the second type of coping "Goal-directed problem-focused" and the strategy problem-solving. It is an excerpt from a planning meeting (PST=Preschool teacher; M=Mother; P=Professional):

Sequence* >*The sequence begins with that the mother and the preschool teacher gives an description of problems with a high chair not fitting the table at the preschool* < PST: those...options available... but that does not feel so funny because then she come from...our table...it is to fasten her table...M: but it feels no fun...because then she becomes outside [the group] PST: we tried to let her have her...she got to sit and have this long spoon...but she comes right at the same height that her mouth is right in the plate M: we were thinking of a regular chair...one of those Tripp-Trapp-chairs with protection...or...do you think it is stupid

for her to sit in one of those PST: if we let her sit with pillows just at the meal (P: no, I actually think you might try> *here follows a long sequence with discussion about how the problem should be solved with footrest and dining chair* <M: otherwise you may well cut off a piece of the table ... (everyone laughs) yes I may take the saw...if I take liberties here...but if you sawing off one...out yes to her chair where she has to sit because she has a definite place for her if I understand right where she sits...so just the edge erodes (all laugh) PST: no I do not know...it is the municipality's furniture so we cannot determine over them (humor)> *the sequence continues with how the problem should be solved* <M: yes but if that does not help...so we try a typical high chair...with the pillow (P:...and to see if there are opportunities for this...then, we can try with one of those [chairs]) (everyday life/routines).

In the third phase, the coping strategies that could be identified were gradually sorted according to the themes. Both the families' as well as the professionals' responses were analyzed according to the four types of positive coping. In addition, eight factors, identified in international research through a systematic literature review (Ylvén et al, 2006), that could be perceived as potential sources of stress were included in the analysis: child's impairment/related conditions, information, lifestyle, everyday life/routines, financial, intervention, responsibility, and support. They were related to the different strategies used by the parents to handle the stressor. This procedure allowed the researcher to investigate whether and how the professionals respond to the families' own coping strategies (Table 2).

Table 2. Sequences showing stressor, family coping, and professional response

VF5 video sequence	Initiative	Stressor	Family coping	Response from professionals	Corr
A	P	CI/RC	PA (Min)	SBP (O)	2
B	M	Ev life/rout; Supp	PE (MA)	SBP (O)	2;2
C	P	Supp	PE (MA)	- (no supp)	0
D	P	CI/RC	GDPF (GS)	GDPF (GS)	1
E	P	Ev life/rout	PA (Ad)	SBP (O)	2
F	P	CI/RC	SBP (O)	SBP (O)	1
G	M	Ev life/rout	SBP (V)	GDPF (PS)	2
H	P	CI/RC	GDPF (PS)	GDPF (PS)	1
I	P	Ev life/rout; Int	PE (MA)	SBP (O)	2;2
J	P	CI/RC	SBP (O)	SBP (O)	1
K	P	CI/RC	SBP (V)	SBP (V)	1

Correspondance: 0=no response; 1=same response; 2=other response

Initiative:

Professional (P); Mother (M)

Stressor:

Child Impairment/Related conditions (CI/RC)

Everyday life/routines (Ev life/rout); Support (Supp); Intervention (Int)

Coping type and strategy:

Positive appraisal (PA); Strategy: Minimizing (Min); Adaptation (Ad)

Goal-directed problem-focused coping (GDPF); Strategy: Problem solving (PS); Goal setting (GS)

Spiritual beliefs and practices (SBP); Strategy: Values (V) Optimism (O)

Positive event (PE); Strategy: Meaningful activities (MA)

Table 2 contains 11 sequences from one session, a videotaped planning meeting with one family. The table shows who initiated the sequence, what type of coping and related strategy is used, response from the professionals, and whether this response corresponds to the strategy used by the parent or represents a different strategy.

Eleven videotaped planning meetings and seven interviews were analyzed (totally 18 recorded sessions). One table was created for each of the 18 recorded sessions. The result is based on 164 sequences - 102 sequences from the videotaped planning meetings and 62 from the interviews.

An independent rater was used to confirm the accuracy of the analysis. Two sessions were randomly selected from the total of the 18 sessions. These two sessions were videotaped planning meetings. Twenty three sequences were cut out and selected into the 12 themes by the independent rater. The agreement was calculated with the formula “number of agreements divided by the total numbers of sequences selected into

the intended theme”. The inter rater agreement for the first session was 83 % and for the second one 81 %.

In the second study (II) the empirical data were analyzed inductively using conventional content analysis (Coffey & Atkinson, 1996; Hsieh & Shannon, 2005). Data consisted of memory-notes ($n=500$), informal information ($n=231$), transcribed data from planning meetings ($n=10$) and interviews ($n=7$). First, all data were read through several times to get a sense of the whole. Words, concepts, and sentences that contained relevant aspects for the research question were then identified and exact words from this text were highlighted. Below shows an example of exact words from memory-notes were sorted after how they were related to relevant aspect for the research questions:

Physical therapy with massage and exercises, physical therapy, gymnastics, physiotherapy, physical therapy and exercise, training of standing shell and stander, fit testing the new standing shell/extra cushion to the dining chair, problems with sucking, new dining chair with different functions, are mainly used at meals/new cup with spout ordered, try the new pacifier and baby bottle, stimulating and good speech development, the personal assistant must always use characters and arrange them in the order, practice a lot of signs, instructions about color significance for vision, “vision day” with tips and exercises to facilitate the child’s ability to see/the child participates well in the exercises, rolling on the floor actively participating, do not want to sit on the side or stand long in the quadruped position/new program of training provided to the assistant, exercise programs at home, e.g. by the coffee table, training program for standing shell and stander, training program with different exercises and in the standing shell (Memory-notes, May, F3)

The excerpt above shows text that was noted in preprinted memory-notes from families and professionals about activities and interventions carried out during one month. Every contact between the two parties was noted by them separately, which resulted in several memory-notes that were sent in each month. The next example comes from informal information, recorded by professionals using Dictaphones. The exact words were sorted after how they were related to aspects relevant for the research questions:

Team meeting need to inform the family about “vision education” either at preschool or that staff comes to hab for teaching staff and more families. Discussion in the team about that family shall participate in communication week. The team talks about communication for the child. Decision, the social worker talks with the family. Informing the team about the offer from SPI and contact persons will send information to families. Meet the dad and talks about the child’s vision, the dad unsure about the meeting at the vision center it had been postponed, suggest they make a call. Should have a meeting with the family after they visit a colleague to inform about SPI, the family was in a hurry, call instead. Called the dad and talked about SPI, decides to send info. Talk with colleague about the child’s vision,

she is also uncertain, things has to be very near the child's eyes. Talking with colleague about the child's vision problems, need for eyeglasses and need for assessment to adapt material. A call from SPI about communication week/Talk with dad who tells that the child sounds more and varied. Talking with colleague about the child's positive development. Meets the family with another colleague, complains positive development, sitting in chair, communication and interaction, using right hand. That is good for the independence training/Meets the dad suggest a meeting to talk about LSS. Mom searched for me, called her and talk with mom about resource at preschool, informing mom about further contact with preschool, recommend a visit, I follow and attend the meeting. Mom calls back when the placement at preschool is ready, I will prove that the resource is needed/Contacting center for assistive technology about a missing chair. Chatting with the dad. Gathering for parents with young children at hab. (Dictaphones, Dec, F3)

The informal information was not recorded in the ordinary work at C-YHS. It was only information for the study, and the tapes were sent in to the researcher once a month.

The initial coding scheme often emanates directly from the text (Hsieh & Shannon, 2005). The exact words that capture key thoughts or concept were labeled for the construction of codes. Most of the key concepts came directly from the participants' words; some were an interpretation from the researcher of what the participants seemed to describe. The numbers of words, concepts, and sentences were 573 from memory notes; 196 from informal information; 47 from videotaped planning meetings; and 30 from interviews, a total of 846 words, concepts, and sentences. From these 846 words, concepts, and sentences, data was extracted. Codes that were related and could be linked together were clustered into 19 subcategories (Hsieh & Shannon, 2005). The 19 subcategories were: body/physical function, activity, communication, nutrition, medical, support, intervening, instructing, assessing, informing, planning, documenting, engaging, consulting, reflecting, hand over, concerns, problem solving, and making decisions. Further, based on relationship among these subcategories, three main categories emerge: focus, action, and collaboration. The 19 subcategories were placed on a time-line that was created for each family. Table 3 shows an example of a time-line for period of five months from one family, starting with a planning meeting.

Table 3. Time line showing content focus in the collaboration at a planning meeting, focus for the action intervening performed the same month, and new decisions and activities four months after the planning meeting (Fam1)

Action: Intervening	Nov	Dec	Jan	Feb	March
Focus	Planning-meeting	Everyday hab	Everyday hab	Everyday hab	Everyday hab
Ph - Body/physiological	5			2	3
A - Activity	3	1		3	2
Com - Communication	3	2	4	5	4
N - Nutrition	2				2
M - Medicine					
S - Family support		1			1
Collaboration					
Parents Concerns	2Com; 2S; 1N				
Problem Solving	1N		4S; 1N		
Decision	1Ph	2Com	2Ph	1S	1Ph; 1Com

The sub-categories were sorted and abstracted into three categories: Focus, Action, and Collaboration. *Focus* was related to the content of the concerns, problems, activities, decisions, and goals, and on the focus of the intervention. *Action* was related to the actions that the concerns, problems, and decisions generated as reported by professionals and parents. *Collaboration* was related to the occasions when parents and professionals met face to face and discussed concerns, problems, and decisions in relation to goals.

To establish credibility (Hsieh & Shannon, 2005) the steps from codes to subcategories and categories were peer reviewed by a member of the research group. In addition, the fact that correspondence tended to be found between the content in the different types of data sources when they were triangulated provides support for the validity of the process. The analysis was an iterative and reflexive process that involved going back and forth between the abstract categories and the empirical data.

In the third study (III) descriptive statistical analyses were carried out to assess data quality in relation to the basic criteria for the main study planned. To generate useful information, within group variance must be large enough to allow for statistical analysis of all subscales and scales. Ideally, the respondents should respond to all items and the response distribution should cover all response alternatives. In a first

analysis of the SPSI-R:L, a table was created in which the respondents' score values were inserted in the five separate problem-solving scales (PPO, NPO, RPS, ICS, and AS). The respondents' score values were compared with the norm group values for each scale in the SPSI-R:L (D'Zurilla et al., 2002). In further analyses of the SPSI-R:L, the individual profiles for each of the 12 respondents were analyzed. The analysis showed different profile patterns among the individuals compared with the profiles in the norm values for SPSI-R:L.

In the final study **IV** data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 19 (IBM SPSS Statistics). Overall, the scores from the leisure activities scales were treated as ordinal data. Descriptive statistics were calculated to explore characteristics of the sample. It was also used to answer the first research question of how involved families with a child with PIMD were in core and balance activities. For between sample comparisons (families with a child with PIMD or TD) Mann-Whitney U tests were used. Chi-square tests (2x2 tables) were used for exploring associations with involvement to a lesser degree in core leisure activities within the group of families with a child with PIMD with the family variables: income ($\leq 400\ 000/\geq 400\ 100$ Swedish crowns), children ($1/>1$), parent employed as personal assistant (yes/no). The first quartile was used as the cut-off score and when $n < 5$ Fischer exact test were used. Descriptive statistics were used to measure how involved families with a child with PIMD were in core and balance activities. For between sample comparisons Mann-Whitney U tests were used. Chi-square tests were used for exploring involvement in core leisure activities within the PIMD group with the family variables: income, children in the family, parent employed as personal assistant.

5.6 ETHICAL CONSIDERATIONS

The two first studies (**I** and **II**) were approved by The Ethical Committee at the Swedish Research Council (Vetenskapsrådet) and received ethical permission for the research project Dimensions in intervention processes – collaboration between families and professionals in Early Intervention for children with disabilities (DIIS) (Dnr. 421-2001-3837). Families and team members at C-YHS giving their consent to participate in the project were informed according to research ethics principles in humanistic-social scientific research developed by The Swedish Council for Research in the

Humanities and Social Sciences – HSFR (2006-06-26, http://www.codex.vr.se/codex_eng/_codex/oversikter/humsam/humsam.html). In the DIIS-project all four requirements formulated in the HSFR's ethical rules were followed, that is requirement for; *information; consent; confidentiality; and employment of research data*. Written consent from families and professionals resulted in permission to use coded data in studies related to the research project DIIS (I and II in the present thesis). Names or places mentioned in the interviews were changed in order to ensure confidentiality. Video- and interview tapes and information about participants were stored in a secure cabinet at the university.

Study III was approved by the Swedish Regional Ethical Board in Stockholm (Dnr. 2009/425-31). In Study III informed consent in traditionally meaning could not be obtained because the participants were anonymous and no personal information was asked for. The participants were well informed that no person that answered the survey could be identified, and therefore the survey could not be excluded after submission. Informed consent in Study III was tantamount to that the participants filled in the survey and submitted it. This anonymity was also obtained when the families sent in the paper-and-pen surveys. The Swedish Regional Ethical Board in Linköping approved the ethical permission for Study IV (Dnr. 2010/324-31).

6 RESULTS

The result of the first study (I) showed that families used the four types of coping; positive reappraisal (PA), goal-directed problem-focused coping (GDPF), spiritual beliefs and practices (SBP), and positive events (PE) identified by Folkman (1997). These types of coping were used in relation to different factors perceived to be stressful for the families. Potential stressors were child impairment/related conditions, information, lifestyle, everyday life/routines, financial, intervention, responsibility, and support. The two types of coping most used by the families were goal-directed problem-focused coping and spiritual beliefs and practices. Goal-directed problem-focused coping was used in relation to the child impairment/related conditions, everyday life/routines, and support. The type spiritual beliefs and practices was most used in relation to the child impairment/related conditions, and everyday life/routines. The third most used type of coping was positive appraisal, and in relation to the child impairment/related conditions and everyday life/routines. When positive events were used by parents, it was in relation to everyday life/routines. Professionals responded very seldom within this type of coping. Goal-directed problem-focused coping and spiritual beliefs and practices were to a very high degree used in issues emanating from stressors related to the child's disability or conditions related to the child's disability and to everyday life/routines. They were also used in relation to support as a potential stressor.

Families most frequently used coping strategies (type of coping in brackets) in descending order was as follows: values (SBP), problem solving (GDPF), minimizing (PA), optimism (SBP), goal-setting/decisions toward goals (GDPF), information searching (GDPF), adaptation (PA), reframing (PA), meaningful activities (PE), humor (PE), existential questions (SBP), and represents good memories (PE). Most often professionals responded in another coping strategy than the strategy used by the family. The professionals responded with the same coping strategy in a quarter of times. This interactional pattern was most common when the family used values as a strategy to handle stressors. The responses from the professionals were mostly with strategies within the type goal-directed problem-focused coping; information, problem solving, goal-setting/decisions toward goals. When families used minimizing, adaptation, meaningful activities, and representing good memories as a coping strategy they received responses emanating from other strategies. In a quarter of the times the professionals did not respond to any of the strategies the family used.

In all, goal-directed problem-focused coping, together with spiritual beliefs and practices were the most frequently used types of coping, and the professionals responded most frequently to strategies within the type goal-directed problem-focused coping. The professionals do encourage the families' use of coping strategies even if responses from professionals often emanate from other coping strategies than those used by parents. Examples are the use of optimism when parents use relation to problems in everyday life and the use of problem solving in relation to the use of values in relation to everyday life problems.

In the next study (II) the results revealed that the intervention process is multifaceted and complex and focus on several parallel lines of intervention, as a consequence of the children's severe impairments. Minor problems were solved at once, but the majority of the issues experienced and raised by the families remained over time. Issues that were longstanding concerned possibilities for their children to be active, physiological consequences of the children's impairments, facilitation of the children's communication, support for the family, and medical needs of the children. From the analysis of the activities based on problems identified at planning meetings in the intervention process three main categories emerged: *focus* that accounted for the content of the intervention, *actions* and *collaboration* that described the processes in the intervention.

The category focus consisted of six subcategories: *body/physiological functions*; *activity*; *communication*; *nutrition*; *medical issues*; and *support*. Each of the subcategories described problem areas identified in relation to children's difficulties and was the focus for actions and collaboration. Because the children had several impairments, activities concerning the child had to focus on more than one of the problem areas to solve one problem. Support most often concerned the whole family and was of emotional, instrumental, appraisal or of informational kind.

The category action consisted of ten subcategories – *intervening*; *instruction*; *assessing*; *informing*; *planning*; *documenting*; *engaging*; *consulting*; *reflecting*; and *handing over*. Parents' concerns, identified problems, and desired goals generated a chain of actions, constantly infused by matters raised in the collaboration, often one issue resulted in several actions. *Intervening* was the most important action and was related to activities performed by professionals with special competence in the different problem areas. Professionals provided *instructions* to family members, assistants, personnel at preschools, and to colleagues about how, e.g. training

programs should be implemented and performed. *Assessment* involved both an initial action and a continuing action monitoring the child's progress. To provide and gather *information* related to different problem areas was another action. An action most time-consuming for professionals, besides intervening, was *planning*. Planning included organization scheduling and coordinating. *Documenting* is an action related to legal security and quality assurance and several protocols were produced at C-YHS. *Engaging* in the families' life situation was an action in relation to all problem areas. Two kinds of engagement were identified; in the children's development, and in the concerns about the families. *Consulting* other professionals was a common action, both team members and experts from outside the C-YHS. *Reflecting* was for example actions in relation to concerns about the work or competence in the team or about regarding parents' perspectives. A time-consuming action was *handing over* equipment, aids, and devices between C-YHS, the pre-school and the home.

The category collaboration consisted of three subcategories: *concerns*, *problems*, and *making decisions*. Concerns and problems were the key to the collaboration and constituted the foundation for activities and interventions. All participating families had a number of *concerns*, about the impact of the impairment on their child's future, about communication, support to the family, and medication. Such concerns were raised by families at planning meetings and set the agenda for several activities and actions. There was a strong correspondence between the concerns families raised at planning meetings and on the actions taken between the meetings. The results showed that all major concerns the families raised at the planning meetings were met with formal decisions at the meeting.

Parents' *problems* referred to existing situations, conditions, or issues that were unresolved, and affecting the child's daily life and family functioning here and now. Some problems could be solved quickly, while others remained over time. When the families described problems at the planning meetings, available solutions were discussed in collaboration. All families raised problems concerning the need of support, both in planning meetings and in everyday intervention. Depending on the support needed it generated several actions; informing; consulting; planning; documenting; engaging; assessing; and handing over. Families, however, also initiated and raised problems in the planning meetings that did not generate any activities or actions.

Decisions could be initiated by the professionals but were made in agreement between the family and professionals, and were always formalized. The results

showed that formal decisions in planning meetings were most often decisions in relation to the concerns or problems experienced and raised by the families. New decisions made between planning meetings affected the actions and the activities performed in the everyday intervention. Some activities performed were not identified as formal decisions at the planning meetings or as new decisions between the meetings. These activities primarily concerned long-term interventions focusing on physical impairments and child development.

The collaboration continued through everyday intervention, and through the activities performed between the planning meetings. Collaboration between the professionals and the families was a process, driven by how the children's impairments affected the families' everyday life, and the accumulation of daily hassles. When parents asked for an activity it was most often in relation to recently experienced problems or concerns. Concerns were often focused on the future whereas problems were focused on the present. There was a strong correspondence between the issues that families raised at planning meetings and on the actions taken between meetings. This is shown through the timelines for each family and interviews with parents. The analyses also showed that the majority of issues that families raised were met by formal decisions. Formal decisions, however, were also made about body/physical functions and activity even if these problems were not family concerns or focused in the collaborative problem solving process at planning meetings. Those decisions were often related to treatment of the child's impairment and highly dependent on expert knowledge in professionals.

The result of the pilot study (III) showed a number of issues important to take in consideration before carrying out the planned major study with the aim to explore how different problem solving styles are related to internal and external resources. One issue concerned quality indicators of the measurements when used in this sample. The results from the analysis of the included questionnaires showed an overall satisfactory score distribution of the Ecocultural Family Interview Questionnaire (EFIQ) and the Goodness-of-fit items. Also all items in the Family Outcome Survey (FOS) showed a satisfactory response distribution, except for one item that showed a ceiling effect. In the Way of Coping Questionnaire (WCQ) and in the Social Problem Solving Inventory (SPSI-R:L) a substantial part of the items showed a floor effect. For the SPSI-R:L the floor effects were observed in three subscales associated with dysfunctional problem solving. Further analysis of the

SPSI-R:L showed that for the Avoidance Style subscale all respondents had score values equal to the norm group average (D’Zurilla et al., 2002). For the Positive Problem Orientation subscale 2/3 of the respondents had a score value equal to the norm group average. Comparison analysis of the other subscales showed larger deviations from the norm group average indicating greater variances in the sample included. The greatest deviation was within the Rational Problem Solving (RPS) subscale where five respondents scored equal to the average of the norm group values, six respondents below and one much below the value of the norm group. Further, the analysis showed different profile patterns among the individuals compared with the profiles in the norm values for SPSI-R:L. One individual had a profile equal to the norm group average across the five problem-solving scales, whereas six individuals had values below the norm group average in one of the scales. Five individual’s had values below the norm group in two out of the five scales, of those one individual also had a value above the norm group value in one of the scales (ICS scale). In all, the analysis of within-group variance indicated that SPSI-R:L can provide information that makes it possible to discriminate between different problem-solving styles in the sample.

The result concerning the strength and the weaknesses of the planned web-based procedures for recruitment of participants and the data collection showed that a number of problems can arise. Adapting paper-and-pen questionnaires to a web-based survey without changing how questions were presented and the range of response alternatives requires a suitable web tool. In the contact with journals and organizations/associations the advertisement for recruiting families had to be adapted to their IT experiences. The journal for parents in need of special support and some of the large organizations had professional web designers, but the nonprofit associations did not. To ensure that the same respondent did not post surveys several times, the survey was designed to have a stop function. The consequence of this stop function was that participants that only filled in the survey partly did not have access to the survey once again if they wished to complete the questionnaire. Some questions in the survey were not applicable to the respondents because those required that the family had an individual plan. In summary the pilot study made visible weakness within the design that have to be considered when planning the major study. Based on the results of the pilot study the following aspects need to be addressed regarding recruitment and completion of the survey:

- The presentation of items and the response alternatives adapted to appropriate use of web-based survey
- Adaptation to respondents experience of using IT-based questionnaires
- Technical aspects of the IT-based instrument

In the last study (**IV**) the results showed that the leisure activities assessed seemed to be of relevance for all the families according to the number of families participating in each of the core and balance activities. The results also showed that core activities were performed more often than balance activities, which is in line with the theoretical construct.

The statistical analysis showed that involvement in family leisure activities within the group of families of children with PIMD varied to a high degree. In addition the analysis showed that those families were involved in core activities more often than in balance activities. The proportion between core leisure activities involvement and balance leisure activities was 1.31. None of the examined family variables; family income; number of children; or parent as personal assistant, showed significant correlations with extent of involvement in leisure activities.

In comparison with families of a child with typically development the families of children with PIMD had a significant lower involvement in leisure activities. Significant differences were found for the total scale as well as for the core and balance subscale respectively. The results were the same independent of which of the two versions of the family leisure activities scales (53 items respectively 22 items) that was analyzed. Analysis of the proportion between core and balance activities indicated that families of children with PIMD had a proportionally higher involvement in core activities than in balance activities compared to families of children with TD.

7 DISCUSSION

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 everyday life. This is examined in the context of the support provided by the Child and Youth Habilitation Services (C-YHS). Two types of family resources, internal and external are considered. Internal resources concern coping strategies and problem solving within the family and external resources concern support provided by professionals at the Child and Youth Habilitation Services (C-YHS).

This thesis is an in-depth investigation of four factors related to family functioning. Those factors are coping, problem solving, support and family activities. Families of children with impairments need to use problem solving to cope with stress in everyday activities. To meet the families in their everyday life and relate to their concerns and problems professionals in support organizations need to know how to enhance and encourage family strengths in coping and problem solving. By combining the expertise of families and professionals in the intervention process the strengths of families in coping with everyday life and routines in everyday life can be enhanced. The level of goal-attainment and success in intervention processes is determined of the combination of factors both within and outside the family, and both internal and external resources for the family needs to be accounted for.

Families' types of coping and coping strategies are related to if and how those are responded to and encouraged in the intervention by professionals. The thesis shows that the types of coping that is most frequently used by families are goal-directed problem-focused coping and spiritual beliefs and practices. The professionals' responses tend to focus on problem solving and goal-setting/decisions. Thus it seems that problem solving is a main component in intervention processes for families to children with impairments. It is also a main component in support from the Child and Youth Habilitation Center (C-YHS). The content of issues discussed between families and professionals at planning meetings are related to activities implemented in the everyday services between meetings. Even here problem solving seems to be a major component in order to reach outcomes related to everyday life activities for families. One outcome of activities is that families experience joyful activities together on a regular basis. Leisure time activities tend to be beneficial for all families and can be a part of

maintaining a balance between challenges and resources in everyday life. Activities patterns in families of children with profound intellectual and multiple disabilities (PIMD) seem to include leisure time activities as part of coping with everyday life. In all, the results of the present thesis show that factors associated with coping and problem solving are necessary in order to maintain and enhance healthy family functioning. It also shows that both internal and external resources are needed in this endeavor. The results from the four studies will be discussed in relation to internal- and external resources and in relation to family functioning.

The main findings were:

Coping types and coping strategies

- families used four types of positive coping; and all types were used in relation to the stressor everyday life/routines
- families used the coping type goal-directed problem-focused most frequently and this was the type of coping that was most frequently encouraged by professionals
- families most frequently used coping strategy was values and this was most often related to information and problem solving in professionals responses

Problem solving

- the problem solving process includes focus, actions, and collaboration
- families concerns and problems raised at planning meetings set the agenda for activities and actions in everyday intervention; these were also formulated as formal decisions in planning meetings
- decisions were made between planning meetings and affected actions and activities performed in everyday intervention, on top of goals decided in planning meetings
- decisions were frequently related to managing families everyday activities

Concerns and problems

- concerns generated specific goals and actions while problems primarily generated actions, but not always specific goals

Involvement in core and balance leisure time activities

- families of children with profound intellectual and multiple disabilities were involved in both core and balance family leisure activities, but to a lesser degree than families of children with typical development

- families of children with profound intellectual and multiple disabilities showed a proportionally higher involvement in core family leisure activities than in balance activities compared to families of children with typical development

As a result of the first two studies the design of a forthcoming study focusing on problem solving in families of children with impairments was developed. The ideas behind the design are to explore how different problem solving styles are related to the families' internal and external resources.

7.1 INTERNAL RESOURCES

The results show that families' use both problem focused and emotional focused coping strategies in relation to perceived stress in everyday life. The type of coping that families used frequently was goal-directed problem-focused. This type of coping refers to strategies to gain control over the situation and facilitate setting up realistic goals through gathering information, planning, and decision making (Folkman, 1997). One way to understand why goal-directed problem-focused coping was used is in relation to the context where the data was collected. The families in study **I** and **II** were encountered in the context of support provision from C-YHS. The planning meetings aimed at collaboration between families and professionals in order to solve problems experienced in the everyday life of families of children with impairments. The families were new in the situation of being a family of a child with impairments and the questions were numerous. The findings show that in planning meetings families search for information about their child's impairments, support, and interventions (**I**), and also in relation to concerns about the future (**II**). Information has been found to be an important coping strategy to manage stress in a new situation, and the use of this coping strategy has been shown in previous studies (Hedov, Wikblad & Annerén, 2002; Hopia, Tomlinson, Paavilainen & Åstedt-Kurki, 2005). The formal information from the professionals at the C-YHS seemed essential for families to develop the knowledge needed to take part in problem solving, participate in decision making, and require support for the family and their child. Although access to information is a way to cope in stressful situation information can also be a source of stress for families. The results show that both the lack of information and the provision of too much information may contribute to family stress (**I**). From the perspective of systems theory this finding could be understood in relation to family boundaries. If the family has *too open boundaries* in which they are not discriminating about a

manageable amount of information they could invite chaos if they are not selective in the quantity or quality of informational resources (von Bertalanffy, 1969; Kaakinen, Gedaly-Duff, Padgett Coelho & Harmon Hanson, 2010). Another aspect of information was formal information from professionals at the C-YHS. It seemed essential for families to process this information to develop the knowledge needed to take part in problem solving, participate in decision making, and require support for the family and their child. Thus information strengthened the links between the professionals and the family in the mesosystem.

In the type goal-directed problem-focused coping problem solving was the most frequently used strategy (I). Families were active in raising problems and being involved in problem solving in the planning meetings. Their use of problem solving as a strategy was expressed in relation to problems experienced in everyday life. Problems were also raised between planning meetings. These problems were explicitly identified early on at the planning meeting. Several problems and concerns related to the child's impairment, and the need for family support tended to remain over time (II). Problem solving strategies in the planning meetings could be explicitly observed. It became evident how the parents alone or together tried to solve problems, and how they described to the professionals how they solved problems at home. It is clear that the complexity of problems influences how much information that needs to be processed to reach a solution of the problem. As mentioned in chapter 3 the character of problems relate differently to the control of the problem solvers (Tallman, 1993). In problems with a correct solution the result is solely dependent on the problem solver's skills, and when the problem is solved there is control over the problem. Problems that require strategies have no correct or wrong solutions. They are valued for the best result that can be achieved under certain circumstances. In this type of problem there may be conflicts of interest which have consequences for the perception of control over the outcome. The control is then partly due to opposing forces. A conflict of interest may occur in the relationship between the families and the professionals. Especially if there are different values or priorities in the micro-systems influencing the negotiation at the meso-system level (Garbarino & Abramowitz, 1992). The findings show that parents were most engaged in and contributed most to the problem solving process when it concerned everyday topics such as the child's everyday functioning and participation, communication, nutrition, and support for the family (II). This indicates that problems in everyday were

experienced as hassles and the family needed to have the problem solved to acknowledge control of the situation.

One type of coping used by families was spiritual beliefs and practices (I). This type of coping refers to strategies used in relation to family values, to keep a positive attitude, and the philosophy of life (Folkman, 1997). Findings show that in this type of coping, families mostly used the coping strategy values (I). Friedman et al (2003) discuss that in families who share a common culture system of ideas, attitudes, and beliefs about what is valuable, consciously or unconsciously, have a strong binding between members. Family values influence how certain critical events are ascribed as being meaningful, and how they respond to commonly held life goals. However, values are not static. As the family develops and depending on life demands priorities shift over time, as well as values. Over time certain values may become more essential influencing family life, family lifestyle and family functioning. Findings show that values were used (I) in relation to several stressors, and mostly in relation to the child impairment/related conditions, support, and everyday life/routines. It is possible to assume that family values are one of the most salient factors influencing the basis for support they require from the C-YHS. In problem solving and in other strategies related to goal-directed problem-focused coping families may express values in a parallel process. Values seem to relate to what families' appreciate most and to thoughts that guide their actions and desires. An example is to ask for support to facilitate a child's participation in home activities or in preschool. For the family the child's participation can be of great value, and means to reach this goal can partly be through intervention focusing on communication or seating. In critical situations values that are commonly held by families may be experienced as being threatened if they are not met properly (Lazarus, 1999). Therefore it is extremely important that professionals are sensitive to values that seem to be involved in problem solving to a high degree. In study II families' concerns involved reflections and speculations concerning the future; how the child's impairment and disabling condition will impact everyday life for the family and their child; how to continue to support the child; how they eventually will be able to communicate with their child. Such concerns raised by families at planning meetings are highly influenced by family values.

In the coping type positive events strategies are used to facilitate everyday life through making things easier by using humor, doing things together that are perceived as meaningful for the family, and telling about positive events in the family

(Folkman,1997). The findings show that families of children with impairments used the strategy doing meaningful activities together to cope with stress in everyday life (**I** and **IV**). This type of coping and the associated strategies may evolve over time. In the beginning of the data collection in the first study (**I**) families were new in the situation of having a child with impairments, and it was not until the end of the data collection, more than 2,5 years later, that those strategies were identified. The results of study **IV**, where families to children with impairment showed involvement in different family leisure activities, contribute to the finding that doing meaningful activities together tend to be beneficial for positive family functioning.

According to Folkman (1997) doing meaningful activities together is a coping strategy that may reduce stress experienced in the daily care of a family member with illness. The meaningful activities must not be major events, but rather ordinary events in daily life, whereof some are planned or other just happens. Such events are meaningful because they give a feeling of connectedness and being cared about and a sense of achievement and self-esteem. They also give a chance to be distracted from the stressful caring situation. These ordinary events or meaningful activities (**I**) can be associated to core family leisure activities (**IV**) which consist of activities requiring little planning that most frequently are home-based and especially important in families with a stressful everyday life (Zabriskie & McCormick, 2001; Dodd, et al, 2009; Townsend & Zabriskie, 2010). Being able to appreciate everyday events in family life is an internal resource for the family.

In relation to internal resources, besides the use of different types of coping and associated coping strategies, families raised different problems and were involved in problem solving, but they also expressed their concerns. Problems were associated with issues “here and now”. They could most often be solved through collaborative problem solving at planning meetings. On the other hand the concerns that parents expressed were often related to the impact of the impairment on the child’s future. Those were most often met with actions taken between meetings. Activities used and suggested by the families influenced the collaboration between the family and the professionals and the actions and interventions that were carried out by the professionals at the C-YHS. The families’ use of problem-focused goal-directed coping and their expression of problems and concerns were also part of strategies to gain external resources.

7.2 EXTERNAL RESOURCES

The results show that families were in need of the support provided by professionals in the context of the C-YHS, and how they took advantage of this resource both in the collaboration at the planning meetings and in the other contacts in between the planning meetings (I and II). The policy of the C-YHS is to work from a family centered approach. This includes recognizing families' strengths and their ways to cope with the situation of being a family of children with impairments (Dunst, Trivette & Deal, 1994; Dunst, Trivette & Hamby, 2007). Findings show that professionals encouraged a number of the families' own coping strategies. (I). The encouragement from the professionals is an important strategy to make families feel empowered, to experience a feeling of being competent in their choices, and attaining reinforcement for their own ideas to solve problems. Receiving encouragement does not necessarily mean that professionals agree with the family's choices. It means to be supportive in finding what the needs of the family are, and to figure out what is important for the family (Steele, Robinson, Hansen, & Widger, 2010; Puotiniemi, et al, 2002; Pelchat & Lefebvre, 2004). The results show that the professionals provided necessary information into the families' problem solving process. The families participated in the problem solving collaboration as equal partners providing their own knowledge about their child and upcoming situations, and were encouraged to formulate their own goals (I). Further, families concerns and problems expressed in the planning meetings were considered by the professionals and followed up in actions and activities later in the everyday intervention (II).

Professionals at the C-YHS adopted the two ways of help-giving described by Dunst et al (2002), a relational behavior and a participatory behavior, in their family centered approach. They encouraged the families' use of coping strategies and by recognizing these coping strategies they recognized family strength. Relational behavior provided encouragement and was aimed at empowering the family, which in the long run improve functioning. Further, the findings showed that the families concerns generated actions and the professionals invited the families in formulating their own goals. This is associated with a participatory behavior and is important in collaborative problem solving. From a family centered model of service provision families are seen as fully capable of making informed choices. Family centeredness means that families can utilize professionals as external resources to strengthen their existing skills and gain support (Dunst, Boyd, Trivette & Hamby, 2002). One of the outcomes of the support provided by C-YHS is that the family has the knowledge and

competence that is needed to support the member with impairments. A long-term goal is to strengthen the family's own resources and reduce the dependency on the support from C-YHS.

The findings show that families raised problems at the planning meetings, but they also expressed concerns (II). Families' concerns have a similar impact on the activities and interventions provided by professionals at C-YHS as problems. Meeting the day-to-day needs of a child with impairments is coupled with relentless concerns about the future which cause considerable emotional distress. Families concerns are important sources of what families' perceive as stressful. McWilliam, Casey and Sims (2009) have found that families receiving early intervention for their child sometimes hesitate to express concerns at a family level, because they think family outcomes are outside the scope of early intervention. Other research shows that listening to families concerns can prevent more emotional problems later on (Murphy, et al, 2006). Glascoe (2000) means that there are advantages of using parents' concerns. It provides a family focused and collaborative approach, where the child's developmental and behavioral problems can be detected. Unlike most screening tests, it facilitates decisions, for example when families need more information or education. The result in the present thesis showed that families concerns and problems raised at planning meetings set the agenda for several activities and actions in everyday intervention (II).

Most of the concerns and problems that families raised in the collaboration between the families and the professionals at planning meeting, but also in everyday intervention between the meetings, were met with formal decisions (II). Formal decisions are written down in the families' individual plan, which is an agreement between the C-YHS and the family. The individual plan is an important document in the intervention process, which reflects the child's/families' needs, goals, interests, and contains activities that are their main priorities.

It seems like the external resources from C-YHC to a certain degree match internal resources in providing intervention, which is a goal in family centered intervention. Family centeredness means that families can utilize the external resource and that professionals strengthen families' existing skills. This can be expressed as a family outcome relating to increased coping, collaborative problem solving and being in control of the intervention process.

7.3 FAMILY FUNCTIONING

The results show that families of children with impairments both use and have access to internal and external resources. Internal and external resources consist of factors facilitating healthy family functioning. From a systems perspective what happens inside the family unit is as important as what happens outside. Family functioning is a complex process including dynamic interactions between developing family members and the environment in diverse phases of the family life cycle, which shapes their social experiences (Denham, 2003). Only a few factors relating to family functioning were explored in the present work. Some of them exist within the family: i.e. internal resources like families coping strategies and problem solving. Others are outside the family: i.e. the external resources, such as support from the C-YHS. When families receive a child with impairments they are in a state of change and readjustment and tend to be more open to the outside environment because they need resources beyond themselves (Rowe Kaakinen & Harmon Hanson, 2010). Families strive to reach balance (homeostasis), and when their own resources are not enough, they need support from the outside to restore balance (Wachs, 2000).

The findings show that most activities from the C-YHS were focused on the child, but when *support* was provided it concerned the whole family and was only partly related to child-driven issues (II). The support to the family was important and the families had different needs. Actions from the professionals were to support the families with problems within the family system, but also in relation to stress factors from outside the family. Families that function well manage to find balance between growth/change and stability/equilibrium in relation to the exchange between the family as a system and its environment (Wright & Leahey, 2000). Providing services to families of children with impairments means to be responsive to families' resources, strengths, concerns, and priorities as well as differences between and within families. The intention with providing service and support to families is an optimal family functioning (Carpenter, 2000).

In line with a systems perspective on family health, family functioning embraces aspects of instrumental functioning (i.e. routine activities of daily living) and expressive functioning (i.e. communication, problem solving, roles, beliefs, alliances and power). These two aspects are interacting and if families experience problems within instrumental functioning, expressive functioning is most often affected (Wright & Leahey, 2009). Families of children with impairments do sometimes experience extraordinary stressors in everyday life, and the functional capacities of the family and its

members are challenged (Denham, 2003). In families of children with challenging behavior the family life change (Myers, Mackintosh & Goin-Kochel, 2009) and the ability to do things together require problem solving skills and different strategies to cope with the situation. This may imply that everyday life and routines is difficult to get to function and be perceived as stressful. Beyond the families' routines, there are other leisure activities families wish to do together in everyday life (I-II and IV). Families' experiences of stress in everyday routines may spill over to those leisure activities that are supposed to provide a sense of meaningfulness and promote positive health. Support from professionals to change the perception of the stress factors (Mellin et al, 2004) may help families to adjust their coping strategies to enhance family well-functioning.

From a family systems perspective, shared leisure has a positive value for the family as a unit and its members, and for promoting family well-functioning. Findings in the present thesis show that families of children with profound intellectual and multiple disability (PIMD) were involved in both core and balance activities, but to a lesser degree than families of children with typically developed children (TD) (IV). According to Townsend and Zabriskie (2010) it is the pattern, i.e. the balance between core and balance leisure activities that is essential. Families that only or to a higher degree are involved in balance family leisure activities may experience that the family's home situation is challenging and families therefore choose activities outside home. This strategy could be a relief in a short term perspective for families of children with problematic behavior, and a way to take a time-out from the ongoing stress felt at home (Folkman & Moskowitz, 2000). Depending on the families' interpretation of the stressful situation their way of coping can be either emotional or problem focused. To give an example: If the situation at home is interpreted as overwhelming and the family decides to leave home to escape or distance from the situation means they cope emotionally. If the interpretation is that it is important to change the situation, e.g. the family decides to break an unsustainable pattern of challenging behavior at home for a visit at zoo, means they cope problem focused.

Further, Townsend and Zabriskie (2010) means, that if balance family leisure activities are predominant, it may affect family functioning negatively. Being involved in core family leisure activities are a strong predictor of healthy family functioning for families of children with impairments. The findings show that the families of children with PIMD (IV) were proportionally involved in core family leisure activities to a higher degree than in balance activities compared to families of children with TD is

consistent with other research (Dodd et al, 2009). Findings also show that families of children with PIMD were involved in both core and balance family leisure activities (IV).

The majority of studies where the core and balance theory have been used report that regularly being involved in both categories of family leisure activities is essential (Zabriskie & McCormick, 2001). The theory of core and balance family leisure activities has its foundation in systems theory. To understand families from a systems theory perspective implies an awareness of families as dynamic systems sensitive for stability and change (Zabriskie & McCormick, 2001; Wachs, 2000; Bornman & Granlund, 2007). According to the core and balance model, core family leisure activities address familiarity and stability in a family by regularly providing family leisure experiences that foster cohesion. Conversely, balance family leisure patterns address novelty and change and provide an opportunity for families to experience change in a relatively comfortable setting (Zabriskie & McCormick, 2001). The involvement in core and balance family leisure activities is essential due to that family systems are striving to reach homeostasis. As a consequence, the family's needs of stability or change, or willingness to change, may vary depending on the demands on the family. It may be purposeful for achieving a healthy family functioning in families of children with impairments to be involved in core family leisure activities since these are associated with stability.

7.4 METHODOLOGICAL CONSIDERATIONS

In the present thesis several methods and approaches were used. The first two studies (I and II) had a longitudinal design where data was collected from different sources (professionals and families), and with different methods. Mixed methods were used to enhance the ecological validity of the study (Bronfenbrenner, 1979). Study I had a longitudinal qualitative multiple case study design. The use of several sources and informants in study I and II allowed for triangulation. Triangulation is one way to establish trustworthiness and other methods were also used. An independent rater was used to confirm the accuracy of the analysis. Two sessions were randomly selected from the total of the 18 sessions. These two sessions were videotaped planning meetings. Twenty three sequences were cut out and selected into the 12 themes by the independent rater. The agreement was calculated with the formula "number of agreements divided by the total numbers of sequences selected into the intended theme". The interrater agreement for the first session was 83 % and for the second one

81 %. In study **II** the steps from words, concepts and sentences to subcategories and categories were peer reviewed by a member of the research group. The fact that correspondence tended to be found between the content in the different types of data sources provides support for the validity of the process. It can be seen as triangulation strengthening the validity of the results obtained.

The data-collection methods used comprised observations of videotaped intervention planning meetings and interviews with parents. These methods provide different types of data; videotaped observations generate information about the “here and now” dialogue, while the interviews provide retrospective information and thoughts about the future. It was planned that two planning meetings and one interview should be collected from each of the participating families, but because of technical problems, data from two families consisted of only one videotape and one interview each. Thus, it was decided that all videotapes and interviews for the 5 families should be used. Using memory notes (**II**) from both families and professionals made it possible to have both parts perception about the content in and purpose of contacts with each other. This strengthens the validity of the analysis.

Data was collected from videotaped planning meetings held approximately twice a year at the C-YHS (**I** and **II**). From the completion of the C-YHS websites in the 21 county councils in Sweden, and information from families about planning meetings, it could be concluded that planning meetings held once every six month is not representative of the real conditions. A methodological issue highlighted in study **II** was that the families could have received more attention from professionals due to their participation in the study. It is not known if the professionals engaged more with the participating families or reflected more on their own performance than would typically be the case (cf with Hawthorne effect).

Two of the instruments included in the third study (**III**) showed a floor effect. In the WCQ eight out of 45 items and in the SPSI-R:L 12 out of 52 items showed a floor effect. Floor- and ceiling effects are due to statistical effects of a scale. A scale with too short span in the response alternatives lack possibilities to estimate higher or lower scores than maximum or minimum value. This is a treat to content validity. In study **III** very few respondents participated, and the observed floor effects could be true due to this fact. WCQ and SPSI-R:L have been tested in larger samples showing satisfactory psychometric properties (Lundqvist & Ahlström, 2006; Gustafsson et al., 2006; D’Zurilla et al, 2002; D’Zurilla, 2011).

Some of the included instruments (Goodness-of-fit and FOS) in the survey used in study **III** required that participants had an individual plan. In the forthcoming major study one of the criteria to participate is that families of children with impairments have an individual plan at the C-YHS. The families who participated in the pilot study were not recruited on the same conditions, and some of them did not have an individual plan, and could not provide responses to all questions. Many families perceived that several questions were almost identical (e.g. in the SPSI-R). This may be that the questions asked for the same thing, but sometimes questions appear to ask for exactly the same information, but include a slight difference of degree which gives effects in the analysis of the questionnaire. When the survey became accessible for completion, no responses were recorded although the built-in counter had registered several visitors. The survey was designed to have a stop function to ensure that the same person did not post several surveys. This resulted in that participants had no access to the survey twice if they wished to complete the questionnaire, or fill it in on another occasion, and as a consequence no completely filled-in surveys were registered. The FOS instrument in study **III** has not been validated in its Swedish version (Ylvén, 2009). This is something needed before implementing the forthcoming major study.

This thesis shows that there are different complexities related to research within the area of focus. Problems related to measuring at a family level were something discussed in an earlier study (Ylvén et al, 2006), noticing that research generalized to family level often are based on data from only mothers. According to Fisher, Kokes, Ransom, Phillips, and Rudd (1985: 213), “. . . most “family” research is based on data produced by individual family members who provide information about their families, rather than on data obtained by studying families directly or including several family members in the same data collection process.” Two of the studies (**I** and **II**) in the present thesis were based on the same data collection. Both mothers and fathers in the five families participated. They participated together in the planning meetings, and sometimes together in the interviews. Individual interviews were conducted with both mothers and fathers. In a few planning meetings, the mother was alone, but there was no planning meeting with only the father. No siblings were present, and the children with impairments were too young to participate. However, because both parents participated together in most meetings and other activities they both contributed to a family perspective of the situation studied. In the last study (**IV**) four types of family constellations were recognizable; single mother/-father and child; single mother/-

father, child and sibling(s); mother, father and child; and mother, father, child and sibling(s). In this study mother contributed to a major degree (78%). In the first part of the Child-PFA (part A) background questions about the family were included, and space was provided to give information about who belonged to the family. The second part of the Child-PFA (part B) contained questions about leisure activities with pre-printed alternatives of family members. Five families from the two samples were excluded from the analyses because the Child-PFA (part B) did not offer opportunities to fill in all varieties in family structure. These sampling issues may have had an impact on the representativeness of the samples.

Researching internal problems encountered is tainted by difficulties, according to Tallman (1993), therefore researchers do create the problems they are interested to examine, giving the researcher options in terms of design. Problems arising in natural environments and “real-world” problems are more difficult to investigate. Research is lacking about how internal problems arise and how individuals behave during the development of problems or problematic situations. The two data collection methods, observations and interviews, used in study **I** and **II**, provided different types of data. Videotaped observations gave information characterized by the immediate situation “here and now”, while the interviews provided retrospective information but also looking ahead. The video observations were ordinary planning meetings following the usual structure, in the natural context of C-YHS, and containing those concerns and problems experienced by families in their everyday life being a family of children with impairments and siblings.

Concepts relating to processes evolve over time, e.g. positive adaptation, are more problematic to measure and study. Ylvén et al (2006) showed that a number of instruments are required to capture such concepts. Family functioning is a concept with similar properties, and includes many aspects depending on how to define the concept. Study **III** describes a forthcoming study about how different problem solving styles are related to internal and external resources. The compiled survey includes questionnaires about factors relating to skills, competencies, and support that may facilitate family functioning. The pilot study (**III**) show that there is still a need for a number of instruments to try to capture processes evolving over time, and most of the questionnaire are measuring at an individual level. Study **IV** adds one more important perspective to family health and family functioning. Shared family leisure activities, especially core family leisure activities are important for families of children with impairments. Additionally, if a family systems theoretical perspective is

used, it claims that several dimensions should be taken in consideration, e.g. who belongs to the family; families resources, interactions, functions, and life cycle (Fridemann, 1995); and the influences from within and from outside the family system (Hanson & Lynch, 2004; Lustig, 1999). The multidimensionality of individual concepts, together with the aspect of time is difficult to measure with concept specific instruments. Capturing the complex reality of family health and family functioning including families internal and external resources require complex methods and careful design of studies.

7.5 CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

Families of children with impairments may experience stressors in their everyday life. To encounter stressors families need different coping strategies, depending on if they perceive the situation as changeable or not, they have to cope emotionally or in a problem focused way. 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. Those are focused in collaborative problem solving together with professionals. When families concerns and problems are considered and result in actions and activities, the more the problem solving becomes adapted to their actual needs in everyday life.

Families' of children with impairments need internal resources to handle challenges 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.

In the practical work with families of children with impairments external support is extremely important. For families new in the situation questions and concerns about the child and the future are sometimes overwhelming. When professionals are engaged in and support families in positive ways in their process of adapting to their child, and to everyday life, by responding to the families ways of coping they may enhance and facilitate healthy family functioning. Encouraging families in their coping does not mean that professionals' responses have to be in the same strategy that the family uses. When families use the strategy problem solving and professionals respond with being optimistic they encourage the family's way to solve problems independently by themselves. Encouragement from professionals is important, but also to follow up by explicitly talking to families about their own coping strategies, and show them how the strategies they use can be used in other situations to enhance coping in new situations.

7.6 FUTURE RESEARCH

In the first two studies, thoughts about resources that facilitate family functioning emerged. It was underlined that several prerequisites are needed to understand factors that enhance healthy family functioning in families of children with impairments. Coping strategies, problem solving skills, knowledge and competence as a family about the child's impairment and related disabilities, formal and informal support, an individual plan taking in account what are important for the individual family, are among those prerequisites. Future research will be focused on implementation of the planned forthcoming study based on the pilot feasibility study in this thesis. The study will be based on factors relating to internal and external resources. Problem solving styles will be related to families' ways of coping and family competence, i.e. internal resources, and also to child characteristics. Problem solving will as well be related to external resources, such as informal network, support from C-YHS, and documentation in individual habilitation plans. The instruments tested in the pilot study will be used and further refined. In addition the experiences of implementing a web-based study will be used in order to provide a format that allows for proper data to be collected.

Finally, one aspect of work with families coping strategies and problem solving is to connect those to family outcomes. The results from the forthcoming study can be used to relate family outcomes as explored in the study about in the fourth study with family coping and problem solving.

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