

Applying the ICF-CY to identify everyday life situations of children and youth with disabilities

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“Ubuntu”

I am what I am because of who we all are

An age-old African concept

ABSTRACT

Four studies were included in this doctoral dissertation aiming to investigate how habilitation professionals perceive the ICF-CY in clinical work and to identify everyday life situations specific for children and youth aged 0-17 years. The ICF-CY was the conceptual framework and since the research was conducted *on* as well as *with* the ICF-CY, the use of the classification runs like a thread through all the work. The design was primarily qualitative and included descriptive and comparative content analyses. Study I was longitudinal, aiming to explore how an implementation of the ICF-CY in Swedish habilitation services was perceived. Studies II-IV were interrelated, aiming to explore children's most common everyday life situations. Content in measures of participation, professionals' perspectives, and external data on parents' perspectives were linked to the ICF-CY and compared. Mixed methods design bridged the Studies III-IV.

Results in Study I indicated that knowledge on the ICF-CY enhanced professionals' awareness of families' views of child functioning and pointed to the need for ICF-CY based assessment and intervention methods focusing on child participation in life situations. A first important issue in this respect was to identify everyday life situations. Two sets of ten everyday life situations related to the ICF-CY component Activities and Participation, chapters d3-d9, were compiled and adopted for younger and older children respectively, establishing a difference in context specificity depending on maturity and growing autonomy. Furthermore, key constructs in the ICF-CY model were discussed, additional ICF-CY linking rules were presented and suggestions for revisions of the ICF linking rules and the ICF-CY were listed. As the sample of everyday life situations reflects the perspectives of adults, further research has to add the perspective of children and youth. The identified everyday life situations will be the basis for the development of code sets included in a screening tool intended for self- or proxy-report of participation from early childhood through adolescence.

KEYWORDS

Adolescent, child, classification, code set, disability, everyday life situation, habilitation, ICF-CY, implementation, interdisciplinary, participation.

LIST OF STUDIES

The present doctoral dissertation is built on the following four studies:

- I. Adolfsson, M., Granlund, M., Björck-Åkesson, E., Ibragimova, N. & Pless, M. (2010). Exploring changes over time in habilitation professionals' perceptions and applications of the International Classification of Functioning, Disability and Health, version for Children and Youth (ICF-CY). *Journal of Rehabilitation Medicine*. 42(7); 670-678.
- II. Adolfsson M., Malmqvist, J., Pless, M. & Granlund, M. (2010). Identifying child functioning from an ICF-CY Perspective. Everyday life situations explored in measures of participation. *Disability and Rehabilitation*. Early Online. 1-15.
- III. Adolfsson, M., Granlund, M. & Pless, M. (accepted). Professionals' views of children's everyday life situations and the relation to participation. *Disability and Rehabilitation*.
- IV. Adolfsson, M. (submitted). Applying the ICF-CY to identify children's everyday life situations. *International Journal of Social Welfare*.

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PREFACE

Children and parents need opportunities to express their opinions and take part of professional knowledge during the habilitation processes, but there is no structured model for family-professional collaboration with negotiation as the essential element. These statements form the basis for the present dissertation, built on my long-term experiences as a physical therapist in habilitation services and on experiences from my masters' thesis. As I followed the development of the WHO's International Classification of Functioning, Disability and Health, version for Children and Youth, ICF-CY, my interest for this global health classification grew. It provided a model for a holistic perspective of children's functioning, shifting focus from body to participation. Engaged in field trials on the ICF-CY, I recognized its potential for use in habilitation processes, indicating enhanced professional awareness of child participation in everyday life situations. Later, when I got the opportunity to refine and test abbreviated ICF-CY questionnaires, I picked up professionals' need of short code sets designed for measuring participation in everyday life situations. This became the topic of this doctoral dissertation, in which I investigate professionals' perceptions of the utility of the ICF-CY, search existing measures to find indicators for everyday life situations, and ask professionals' about their views of such. At last, I borrow data from other researchers to integrate the views of parents. Still, the views of children are missing but they will be asked for when this basic work is finished. It is easier for the children to reflect on a set of suggested everyday life situations than having open questions to respond to.

My long-term goal is a screening tool developed in collaboration with children and youth, their parents and professionals and focusing on participation in everyday life situations. The basic premise is that active participation in assessment will increase children's understanding of their unique situation and enhance their motivation for interventions when needed.

I hope to get continued opportunities until my dream is fulfilled: a digital survey installed in computers placed in habilitation waiting rooms encouraging children to tell what matters most for them and making parents realize that habilitation services focus on support for handling everyday life rather than normalizing children and their body functions.

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ABBREVIATIONS

ADL	Activities of Daily Living
CP	Cerebral Palsy
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health, version for Children and Youth
ICIDH	International Classification of Impairments, Disabilities and Handicaps
LIFE-H	Assessment of Life Habits for children
UN	United Nations
UNCRC	UN Convention on the Rights of the Child
UNCRPWD	UN Convention on the Rights of Persons with Disabilities
UNESCO	UN Educational, Scientific and Cultural Organization
WHO	World Health Organization
WHO-FIC	WHO Family of International Classifications
b	Body functions (according to the ICF/ICF-CY)
s	Body structures (according to the ICF/ICF-CY)
d	Activities and participation (according to the ICF/ICF-CY)
e	Environmental factors (according to the ICF/ICF-CY)
a	Activities (according to the ICF/ICF-CY)
p	Participation (according to the ICF/ICF-CY)

I INTRODUCTION

One can assume that everyday life situations for children and youth with disabilities are the same as for all children even if they involve different conditions. These differences might be due to environmental opportunities, which are largely dependent on how families provide structures for children's everyday life situations. It is the right of families to have access to resources and opportunities to support the development of children so they can live their lives as they themselves have envisaged (UN, 1989). The long-term goal of the present dissertation is a screening tool providing children and parents opportunities to express their opinions during habilitation processes and guide individualized assessment and intervention planning. As preparation for future development of such a tool, everyday life situations of children of different ages are identified.

Children with disabilities are mostly like children without disabilities and their families are very much like other families. In this dissertation, the construct of *family* means parents, their children, and in some cases other close relatives that live together in the same dwelling (Balton, 2009). The construct of *parent* means the primary caregiver. Parents use various coping strategies, make suitable adaptations of family routines when children grow, and strive for child-family interaction in order to achieve family functioning (Turnbull et al., 2007; Weisner & Gallimore, 1994; Wilder, 2008; Ylvén & Granlund, 2009). However, families of children with disabilities might need supplemental information, knowledge, and support to solve problems and manage requirements of everyday life (Högberg, 1996; Larsson, 2001; Wilder, 2008; Ylvén & Granlund, 2009). In Sweden, support to families is offered by habilitation services with interdisciplinary teams including professions representing medical, social, psychological, and pedagogical disciplines (Björck-Åkesson & Granlund, 2005; Granat, Lagander, & Börjesson, 2002). Families and professionals do not always agree on family needs and sometimes professionals bring up their own ideas rather than listen to the others, implying a risk for children and parents to be given a peripheral role in intervention planning and goal setting (Högberg, 1996; Larsson, 2001; McCormack, McLeod, Harrison, & McAllister, 2010; Thomas-Stonell, Oddson, Robertson, & Rosenbaum, 2009; Wilder, 2008). The starting-point

for this dissertation, in which the construct of *children* is used for individuals 0-17 years of age, is that a supportive relationship, based on family-professional collaboration and professionals' trust in families' capabilities, are the cornerstones for fruitful collaboration to enhance child development and well-being. Although the perspectives are Swedish, data gathered from other cultures are included to broaden the views.

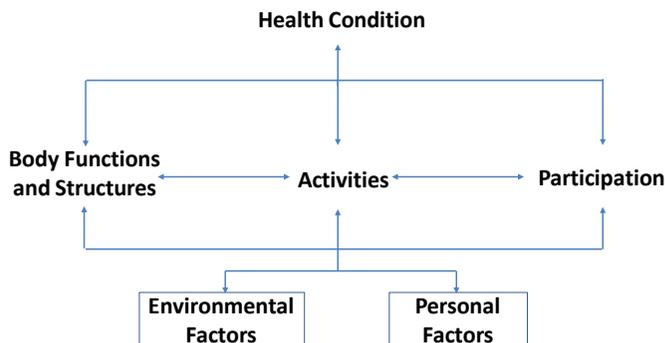


Figure 1.1. The ICF/ICF-CY model including six interactive dimensions of functioning and disability as the conceptual framework of the present dissertation (WHO, 2007; p17).

Life situations are episodes that occur in natural environments where children spend time. *Everyday* life situations occur regularly, e.g. eating dinner, compared with other situations that occur less frequent, e.g. Christmas parties, or life situations that indicate transition phases in life, e.g. becoming a high school student. Since children's involvement in everyday life situations is largely dependent on environmental factors in addition to individual factors, their participation must be considered from multiple perspectives. In this dissertation, the WHO International Classification of Functioning, Disability and Health, ICF, version for Children and Youth, ICF-CY, constitutes an overarching conceptual framework for discussions about how children participate in everyday life situations (Figure 1.1) (WHO, 2007). In addition to participation, which is the social dimension of functioning, the ICF-CY model includes three individual dimensions: body functions, i.e. mental and physiological functions; body structures, i.e. anatomical parts; and activities, i.e. the execution of tasks or actions. The model also includes two contextual dimensions of personal factors and environmental factors. The ICF-CY covers the full range of childhood, 0-17 years, and is a univer-

sal model suitable for all children, not only children with disabilities. ICF-CY code sets include a limited content that is identified as essential for a specific purpose and possible to use across diagnosis to describe and profile children’s functioning and disability (Simeonsson, 2009b).

Code sets focusing on children’s participation can provide information about how children with disabilities deal with everyday life. A future screening tool will include code sets for everyday life situations and as preparation, the present dissertation investigated the utility of the ICF-CY in clinical work and identified everyday life situations specific for children and youth from an adult perspective. It was expected to provide opinions about what professionals and parents think is important for children based on observations.

Further research is planned to get knowledge on how everyday life situations can be understood from the perspective of children with and without disabilities. It could be possible to interview children as young as 4 years of age (Docherty & Sandelowski, 1999; Lidström, 2005; Poole & Lamb, 1998). It is assumed that children easier provide information if they are asked to discuss specific activities, i.e. a list of suggested everyday life situations, rather than using broad, open-ended questions (Peterson-Sweeney, 2005; Sturges, Rodger, & Ozanne, 2002). Most likely, such a strategy allows that the ideas to be discussed are more understandable for children.

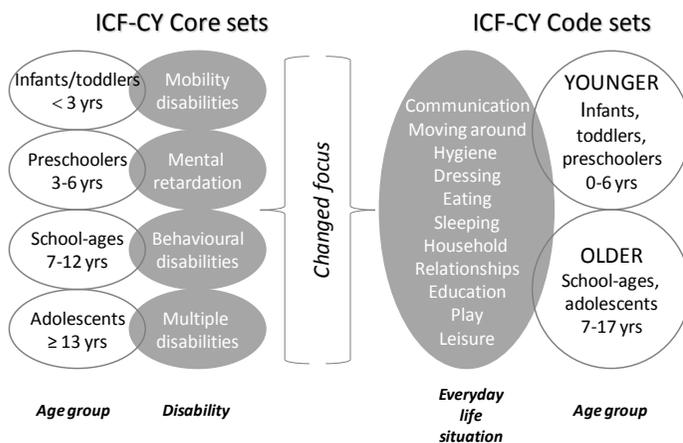


Figure 1.2. The changed focus for a future screening tool - from the initial plan of core sets to code sets.

During the progress of the dissertation, the initial plan to develop core sets adapted to four age groups and four types of disabilities changed. The findings in Study I indicated the relevance of using the ICF-CY, but also the need for proper tools directing individualized planning of interventions. In addition, research established that medical diagnoses provide information neither on functional status nor on participation in everyday life situations (Law et al., 2004; Lee, 2011; Lillvist, 2010; Rutter, 2010; Simeonsson, 2006; Stein, 2006; WHO, 2007). This led to the decision to develop participation focused code sets adapted to everyday life situations and to relevant age groups (Figure 1.2). The results in the present dissertation have implications for future development of an interdisciplinary screening tool to be used for self- or proxy-reports from early childhood through adolescence. The tool is intended to identify individual needs and potential developmental areas as a basis for more comprehensive assessment of children with disabilities. Because of the need to move beyond diagnoses to describe functioning, it is expected to meet the professionals' request for a proper tool capturing predictors of participation and to attain usefulness as a collaborative screening tool. Although this dissertation is limited to the perspective of adults, children's perspective will govern the final list of everyday life situations, their titles, and content in the future screening tool.

2 CONCEPTUAL FRAMEWORK

Functioning and disability are reverse constructs in the multi-dimensional ICF-CY framework of health. A central question is What dimensions are to be considered when describing children's everyday life situations? This section presents the ICF-CY that constitutes the conceptual framework for the present dissertation, how it may be used in clinical work, critique, and the need of reduced sets of categories.

2.1 ICF-CY

The International Classification of Functioning, Disability and Health, ICF, with its version for Children and Youth, ICF-CY, is a universal and multi-dimensional conceptual framework to health, human functioning, and disability. It was developed by the WHO to provide a common language for various organizations, users, and caregivers to communicate people's functional states and life situations (Darzins, Fone, & Darzins, 2006; IOM, 2007; Rosenbaum & Stewart, 2004; WHO, 2001, 2007; Üstun, Chatterji, Bickenbach, Kostanjsek, & Schneider, 2003). Trials have explored benefits of the common language in terms of support for professionals to clarify their team roles and facilitation of team discussions (Ibragimova, Granlund, & Björck-Åkesson, 2009; Rentsch et al., 2003; Tempest & McIntyre, 2006). The ICF or ICF-CY cannot replace professional language but serve as a structure for information and a tool for communication.

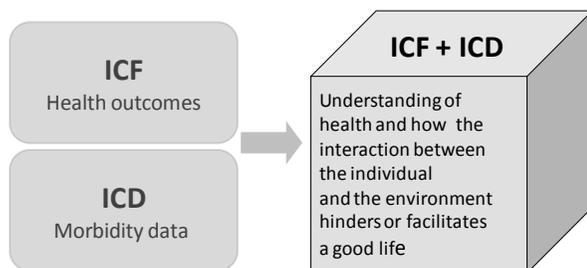


Figure 2.1. WHO's international classifications of health and functioning, ICD and ICF. Adapted from Pless & Granlund (2011; p44).

The WHO Family of International Classifications, WHO-FIC, provides frameworks to describe a wide range of information about health. The ICF, which is the adult version that was published in 2001, and the ICF-CY, which came six years later, are the functional frameworks that classify health outcomes (WHO, 2001; 2007). They are complementary to the International Classification of Diseases, Tenth Revision, ICD-10, which is an etiological framework classifying morbidity data, based on medical diagnoses of diseases and other health problems. Soon after the publication of the ICF, WHO's General Secretary Gro Harlem-Brundtland expressed the expectation that the ICF and ICD together may enhance the "understanding of health and how the interaction between the individual and the environment hinders or facilitates a good life" (Figure 2.1). All classifications are undergoing continuous revisions.

The ICF and ICF-CY are universal in the sense that they can be used to describe functioning of all people, not only persons with disabilities. It depicts equality regarding opportunities and rights and it purports to be useable across cultures (Bickenbach, 2009; Bickenbach, Chatterji, Badley, & Ustun, 1999). The ICF/ICF-CY is based on an integration of the social model and medical model of disability and focuses on components of health rather than on consequences of diseases (Hacking, 2004; Stiker, 1999; WHO, 2001; 2007). Multiple ICF-CY dimensions synthesize biological, psychological, social, and environmental aspects of child functioning. The key construct in the classification is the neutral term participation, defined as involvement in life situations. The construct intends to substitute the negative term handicap.

The ICF-CY includes all content in the adult version ICF with additional content intended to cover developmental characteristics of children from birth up to 18 years of age (Leonardi & Martinuzzi, 2009; Simeonsson et al., 2003; Simeonsson, Sauer-Lee, Granlund, & Björck-Åkesson, 2010; WHO, 2007). Thus, the ICF-CY provides multiple perspectives of functioning, which among children include for example mental functions of attention, memory, and perception as well as activities of play, learning, family life, and education. In this dissertation, the ICF-CY was consistently used.

2.2 THE ICF-CY MODEL

The ICF-CY is an interactive health model. It illustrates a complex relationship between six dimensions: health conditions; bodily factors, i.e. body functions and structures; activities, such as abilities to perform actions; participation, such as the experience of being part of society; and contextual factors, i.e. environmental factors and personal factors (Figure 2.2). Descriptions of functional and environmental aspects are needed to achieve a holistic view of children's everyday life situations since the naming of a diagnosed disorder or disease cannot depict everyday functioning in a child (Florian et al., 2006; Grimby, Harms-Ringdahl, Morgell, Nordenskiöld, & Stibrant Sunnerhagen, 2005; Reed et al., 2005; WHO, 2001). Functional aspects encompass how children use their individual resources and how involved they are in contexts where they usually spend time. Environmental factors add information about how the context affects a child's functioning (McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006; WHO, 2007). Since the ICF-CY provides a framework and a structure for collecting and organizing information, it may influence assessment, intervention planning, and outcome evaluation (Bruyère, Van Looy, & Peterson, 2005; Leonardi & Martinuzzi, 2009; Reed, et al., 2005; Rentsch, et al., 2003). By using a neutral terminology, the framework may support descriptions of a person's strengths as well as weaknesses.

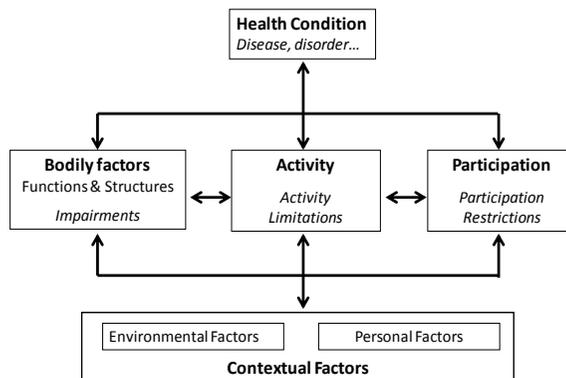


Figure 2.2. The ICF-CY model including constructs capturing functioning and disability. Adapted from Simeonsson (2009a) and WHO (2007).

The model of health becomes a model of disability when a severity qualifier is applied to indicate impaired functioning, i.e. the extent of impairments, activity limitations, or participation restrictions (Figure 2.2). To describe children's problems related to activities and participation, a scale ranging from 0 (no difficulty) to 4 (complete difficulty) is available providing one qualifier to quantify capacity and one for performance. The capacity qualifier indicates activity and describes a child's ability to execute a task or an action, indicating the highest probable level of functioning in a given situation at a given time (WHO, 2007). This information can for example be provided by standardized tests. The performance qualifier describes what children actually do in the natural environments where they spend time. It indicates a societal context and causes confusion because it can be understood as either 'involvement in a life situation' or 'lived experience'. In the ICF-CY, performance is the only possible indicator of participation. It is however suggested that participation is not only about taking part in what happens in everyday life situations, it is also about being engaged, being accepted, and having access (WHO, 2007; p13). These aspects are not easily measured without asking the children or their caregivers about their opinion. To describe the impact of environmental factors on children's functioning there are two available qualifiers applied to indicate facilitating factors and/or barriers.

Because the ICF-CY provides a structure to organize information about children's life situations from multiple sources, it may serve as a *screening tool*, not to be confused with *assessment measures* that most often provide protocols to quantify information (Simeonsson, et al., 2010; WHO, 2007). By that, it does not classify children but defines factors of importance for children's health. These factors include the environment, which is not common in assessment measures, indicating a shift from diagnoses to function. This means that children with disabilities are not classified 'as a diagnosis' but rather described as children with functional problems in specific situations. From this point of view, the use of the ICF-CY may change the way professionals develop intervention programs so that they are based on functioning, e.g. 'interventions for children with communication problems' rather than 'interventions for children with aphasia'. Besides, professionals may differentiate how individual problems relate to the six dimensions in the ICF-CY model in order to individualize intervention planning.

2.3 THE ICF-CY CLASSIFICATION

The ICF-CY classification of codes includes four components with a structure that is displayed in figure 2.3. Compared with the model (see Figure 2.2.), the body dimension is divided into two parallel components, functions and structures, and the two dimensions activities and participation are merged into one component. Body functions and body structures cover all body systems. Functions encompass the physiological functions of body systems, psychological functions included. Body structures include anatomical parts of the body such as limbs and organs, including the brain. The component Activities and Participation covers the full range of life areas, from basic learning to social tasks. Environmental factors include physical, social, and attitudinal factors. Finally, Personal factors provide the background of a child’s life and living, such as age, gender, race, habits. These factors are not yet classified because of the large social and cultural variance associated with them (WHO, 2007).

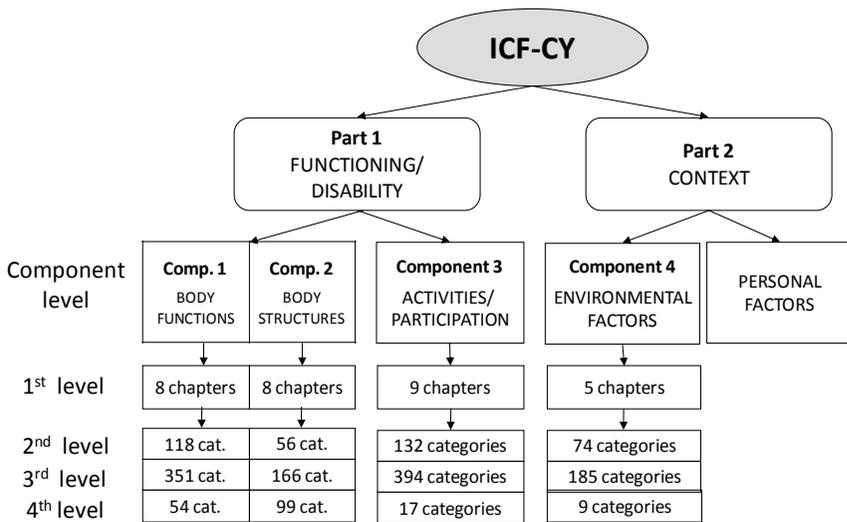


Figure 2.3. The structure of the WHO International Classification of Functioning, Disability and Health, version for Children and Youth (ICF-CY). Adapted from Cieza and Stucki (2008) and Simeonsson et al. (2010).

Each of the four components consists of chapters, in the ICF-CY also called domains, in which categories with titles and associated definitions are listed hierarchically with increasingly detailed categories on second, third,

and in some cases fourth level (Cieza & Stucki, 2008; Simeonsson, et al., 2010; WHO, 2001). This dissertation focuses on 1st and 2nd level categories in the component Activities and Participation.

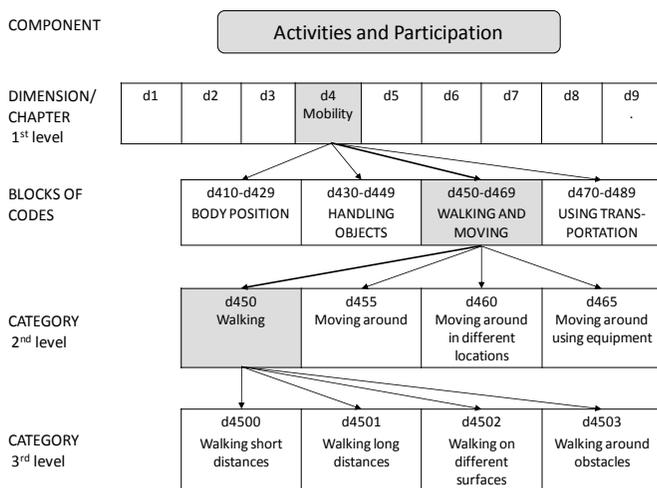


Figure 2.4. Hierarchically listed categories in the component Activities and Participation, chapter d4 Mobility. Adapted from Pless & Granlund (2011; p 54).

Each category has an alphanumeric code starting with a letter to denote component followed by numbers to denote level of categories (Figure 2.4). When suitable, related categories are merged into blocks of codes. The ICF-CY coding system enables linkage of information in measures or other key elements in an intervention process to ICF-CY chapters and categories facilitating comparison of data (Cieza et al., 2002; Cieza et al., 2005; Xiong & Hartley, 2008). As an example, table 2.1 displays how the content in seven measures investigated in Study II of the present dissertation are linked to the activities and participation chapters. Among these, measure 6 is related to all nine chapters whereas measure 4 includes content related to one single chapter. The comparison also provides the information that all seven measures include content related to the chapter d6, i.e. Domestic life.

Table 2.1 *Comparison of content in a sample of measures of participation linked to the nine ICF-CY Activities and Participation chapters (d) (adapted from Study II of the present dissertation)*

ICF-CY chapter	Measure no.						
	1	2	3	4	5	6	7
d1						X	
d2			X			X	
d3		X	X			X	
d4	X		X		X	X	
d5	X		X		X	X	
d6	X	X	X	X	X	X	X
d7						X	
d8	X	X	X		X	X	X
d9	X	X	X		X	X	X

To understand and use the multiple ICF-CY dimensions of functioning and disability in daily work, professionals' awareness of the model in addition to knowledge of the chapters on first ICF-CY level may be sufficient. For interdisciplinary use, a selection of appropriate second level categories is recommended for an overall description of functioning whereas categories on third and fourth level may be useful for in-depth discipline-specific investigations (WHO, 2007). The classification may be seen as a comprehensive dictionary of 1685 ICF-CY categories relevant for describing functioning (Cieza & Stucki, 2008; Simeonsson, et al., 2010).

This dissertation focuses on the ICF-CY both for the study of utility (Study I) and as a conceptual framework in coding and analyzing data (Studies II-IV). A rationale to focus on the ICF-CY was a previous understanding of the classification as a model for broad descriptions of functional status, capturing children's full range of life areas, and probably affecting interdisciplinary work (Bruyère, et al., 2005; Ibragimova et al., 2009).

2.4 CRITIQUE OF THE ICF OR ICF-CY

With the implementation of the ICF, problems have been identified concerning the conceptual framework, the linguistic form, and various perspectives of functioning in the classification. For example, Pfeiffer (2002a; 2002b) highlights the impossibility to find terms fitting all languages and cultures. He argues that the classification maintains a medical perspective,

objectifies disability as a deficit, and conveys stereotypes about people with disabilities. Also Conti-Becker (2009) argues that the focus is still on biological factors and that personal factors have been neglected. Other conceptual questions concern definitions of key constructs such as capacity and performance, activity and participation, and to what extent organizations should focus on one or the other (Nordenfelt, 2003, 2006; Whiteneck, 2006; Whiteneck & Dijkers, 2009). Nordenfelt (2006), for example, states that capacity should be the main interest for healthcare. He argues that a focus on performance is problematic in a health classification, claiming that it shifts the focus from the ability to perform an activity to the actual performance of an activity. In addition, Nordenfelt (2006) points to the lack of the construct of 'will' in the classification. Since observed performance is perceived as too limited to fully understand participation, this lack of a subjective dimension of functioning has been widely discussed (Badley, 2008; Coster & Khetani, 2007; Granlund et al., Accepted; Hemmingsson & Jonsson, 2005; McConachie, et al., 2006; Perenboom & Chorus, 2003; Ueda & Okawa, 2003; Whiteneck, 2006; Whiteneck & Dijkers, 2009). The importance of distinguishing objective and subjective dimensions in identifying the constructs of activity and participation is obvious with reference to Whiteneck (2006). As other researchers (e.g. Egilson & Traustadóttir, 2009), he also points to the need to develop the contextual perspective of functioning. The current one-dimensional view of environmental factors as either facilitators or barriers may be one shortcoming since it is to a high extent dependent on the situation.

Critical comments on feasibility of use have been raised even though many professionals consider it meaningful to use the ICF and ICF-CY in clinical settings. The concerns focus on not getting concrete guidance on *how* to look at an individuals' functional potential, since the classification is limited to facilitate decisions of *what* to consider (Allet, Bürge, & Monnin, 2008). Although it provides a common language, the concepts of the classification is not yet incorporated into clinical practice and several researchers depict the lack of client-centered, self-reported measures of participation with a reasonable number of categories. (Allet, et al., 2008; Bagnato, 2005; Boyd & Hays, 2001; Coster & Khetani, 2007; Darrah, 2008; Hemmingsson & Jonsson, 2005; Ibragimova, et al., 2009; McConachie, et al., 2006; Morris, Kurinczuk, & Fitzpatrick, 2005; Msall, 2005; Saarela Holmberg & Lindmark, 2008; Simeonsson, et al., 2010). Despite those concerns and crit-

ical aspects, the ICF-CY is chosen as conceptual framework in this dissertation. It is anticipated to become a useful tool within services for children with disabilities, providing a framework for problem solving and constituting a common language, bridging professionals and families (Beckung & Hagberg, 2002; Darrah, 2008; Ibragimova, et al., 2009). In addition, a focus on the actual performance of an activity in everyday life, rather than the ability to perform an activity in a health care setting, is in line with the specific task for such services.

2.5 CODE SETS

For clinical use, the comprehensiveness of the ICF-CY is a challenge. Therefore, reduced sets of categories have been defined as standard minimum content areas to be used for specific purposes. They constitute general agreed-on lists of essential categories aiming at directing what to measure, not how to measure, and the lists might be used as checklists for practitioners (Cieza, Ewert, et al., 2004; Escorpizo et al., 2010). For health conditions, such lists are talked about as *core sets*, focus on symptoms, and have been developed for adults with various diagnoses, for example low back pain, depression, and stroke (Cieza, Chatterji, et al., 2004; Cieza et al., 2004; Geyh, Cieza, et al., 2004). Core sets are also under development for children, examples are children with severe disabilities and cerebral palsy (CP) (Melchiorson & Östergaard, 2010; Verschuren et al., 2011). Brief ICF Core Sets include 10-20 categories to be used for clinical studies or population surveys whereas Comprehensive ICF Core Sets include approximately 100 categories aiming to guide multidisciplinary assessments.

Code sets focus on functioning and are sets of essential categories to be used for specific purposes across diagnosed health conditions (Simeonsson, 2009b). Code sets may focus on service settings such as early childhood intervention or education. For children, developmental codes sets and codes sets for communication have been defined (Ellingsen, 2011; Rowland, personal contact, 21st of June, 2011). However, the use of the terms ‘core sets’ and ‘code sets’ is not yet consistent. For example, the lists of essential categories aimed for specific purposes such as acute hospital rehabilitation or vocational rehabilitation are presented as ‘core sets’ although they

do not relate to specific health conditions (Escorpizo, et al., 2010; Grill, Ewert, Chatterji, Kostanjsek, & Stucki, 2005).

The present dissertation intends to prepare for development of code sets by identifying a set of everyday life situations as a basis for future development of brief code sets for child participation in everyday life situations. The aim is to guide individualized assessment and intervention planning (Figure 2.5). During the development process, several perspectives will be considered: researchers' (sought in literature), clinicians' (professionals), and users' (parents and children). The children's perspective will be focused in future research since they usually have a different understanding and experience of the world than adults (Garth & Aroni, 2003).

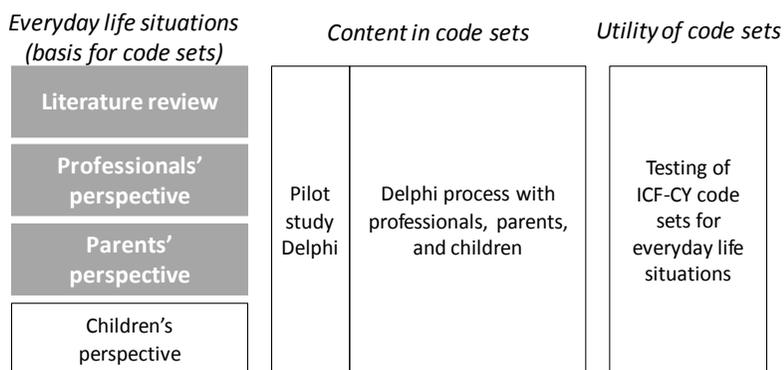


Figure 2.5. Development process of ICF-CY code sets for everyday life situations. Gray marked boxes are included in the present research.

In the future development of ICF-CY code sets for everyday life situations, Delphi processes will be conducted to identify content for each code set, most likely beginning with an initial list of categories based on ICF-CY developmental code sets for children (Ellingsen, 2011). Delphi processes have previously been used to identify the ICF/ICF-CY categories most relevant for core sets or code sets, (Cieza, Ewert, et al., 2004; Ellingsen, 2011; Weigl et al., 2004). It is characterized as a structured, consensus building process mostly conducted in three rounds and with four characteristics: anonymity, iteration with controlled feedback, statistical group response, and expert input. Over the rounds, the process reduces an initial long list of categories

and the participants are informed of the collective opinion, given opportunity to change opinions. When the content in the code sets for everyday life situations have been identified, the final short lists of categories are assumed significant in explaining participation. Despite the risk that essential areas are overlooked by limiting the comprehensive framework, a set of everyday life situations and the categories included in the code sets may serve as valuable window openers into the ICF-CY (Ibragimova, et al., 2009) and as such become usable in dialogues between professionals and families.

3 PARTICIPATION

Participation is a key construct of the ICF-CY. Central questions are How to capture the meaning of the construct? and How to relate it to everyday life situations? This section deals with these questions and the prerequisites for child participation.

3.1 THE CONSTRUCT OF PARTICIPATION

Participation is a key construct of the ICF-CY. The construct is described as children's involvement in life situations (WHO, 2007) and by Eriksson and Granlund (2004b) defined as "a feeling of belonging and engagement, experienced by the individual in relation to being active in a certain context". Consistent with other researchers, this highlights the importance of considering how children experience a life situation, not only how they perform tasks (Jette, Haley, & Kooyoomjian, 2003; King et al., 2007; King et al., 2010). The operationalisation of the construct of participation has been discussed ever since the classification was published with attention directed to two possible interpretations of the closely related construct of performance that is defined as "what an individual does in his or her current environment" (WHO, 2007). The uncertainties may be due to dual conceptual roots, based on either a sociological or a psychological perspective (Granlund, et al., Accepted; Maxwell & Granlund, 2011). The sociological perspective is about availability and accessibility to everyday activities. These aspects show how frequently children attend activities, aspects that might be objectively evaluated. However, the psychological perspective considers the intensity of children's involvement or engagement in activities (Granlund, et al., Accepted; King, et al., 2010). Such perspectives reflect how individual children manage and experience a certain situation and the validity is best evaluated by the children themselves. According to King et al. (2007; 2010), they constitute affective and motivational aspects of participation, such as enjoyment and preference, and can tell adults what matters most for each child.

Two more aspects of participation are the context and environment, i.e. the current life situation in addition to the conditions under which activities take place including where and with whom (Granlund, et al., Accepted;

King, et al., 2010). The context creates conditions for attendance and involvement and children's participation in different contexts is likely to vary due to environmental factors (Maxwell & Granlund, 2011; Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001). Those factors affect a child's attendance in activities by facilitating *accessibility* in terms of physical, social and psychological elements of the environment or *availability* in terms of provision of resources and facilities. The intensity of a child's involvement within an everyday life situation depends on how activities are accommodated to and accepted by the child (King et al., 2004; King et al., 2006; Simeonsson, et al., 2001). In the ICF-CY model, the position of the environment is clear but the context in terms of life situations that are closely tied to participation is not pointed out.

3.2 ACTIVITY VERSUS PARTICIPATION

In the ICF-CY classification, the construct of participation is not clearly distinguished from activity, described as "the execution of a task or action by an individual" (WHO, 2007). The two constructs are not linked to specific chapters (domains) within the component Activities and Participation. An explanation is given in ICF-CY, section 4.2: "differentiating between 'individual' and 'societal' perspectives on the basis of domains has not been possible given international variation and differences in the approaches of professionals and theoretical frameworks" (p14). Therefore, the code scheme for the component provides a single combined list of nine chapters indicating life areas (Table 3.1). To structure the relationships between activity and participation, four alternative options are presented in Annex 3: (1) distinct sets of activities and participation chapters, (2) partial overlap between sets of activities and participation chapters, (3) using detailed categories as activities and broad categories as participation with or without overlap, and (4) use the same chapters for both activity and participation with total overlap of chapters. In addition to these options, the single list can be used to differentiate activity and participation in users' own operational ways (ICF-CY, section 4.2).

Table 3.1 *Chapters in the ICF-CY component Activities and Participation*

Chapter code	Chapter name
d1	Learning and applying knowledge
d2	General tasks and demands
d3	Communication
d4	Mobility
d5	Self-care
d6	Domestic life
d7	Interpersonal interactions and relationships
d8	Major life areas
d9	Community, social and civic life

Some researchers have suggested the distribution of chapters and categories relating to activities and participation as a continuum of volition from reflexes to intentional actions with increased degree of autonomy (McConachie, et al., 2006) but also as a continuum of task complexity from simple to complex actions with increased degree of social involvement (Badley, 2008; Coster & Khetani, 2007) (Figure 3.1).

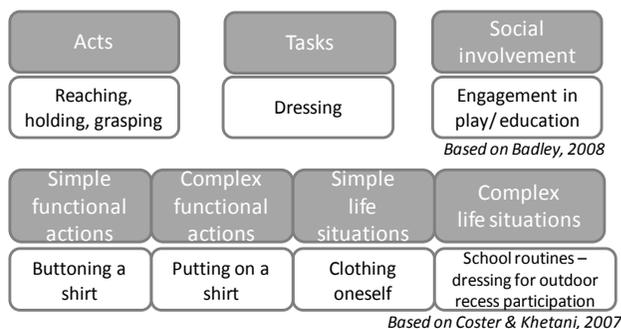


Figure 3.1. Examples of activities along a suggested continuum of task complexity.

As a contribution to clarify the distinction between the constructs, Badley (2008) introduced three subcomponents replacing the constructs of activity and participation. *Acts* were defined as general things that a person can do independent of context or purpose, in accordance with the WHO defini-

tion of capacity. It relates to functioning of the person as a whole, for example eating and talking, whereas body functions might be chewing and articulation functions and body structures are teeth and tongue. *Tasks* were defined as the purposeful things people do in daily life in a specific context. It is for example about ADL (Activities of Daily Living), such as dressing, washing body parts, and other specific tasks that are carried out as part of everyday life, not always performed by motivation or of free will. *Societal involvement* focused on how the individual acts “in different socially or culturally recognized areas of human endeavor” (p. 2339), i.e. in everyday life situations. It was connected with a social role, such as studentship or parenting, and dependent on personal preferences and opportunities. Badley (2008) depicted *environmental factors* as scene setters that determine the conditions and requirements for participation in everyday life situations.

Based on what has been discussed in section 3.1-3.2, Study III in the dissertation presented *participation* as “children’s choice to do activities in specific situations. It also reflects the extent to which the child actively engages in the purposeful activities people do in daily life in different contexts, for example playing in the schoolyard with friends or eating with family. It is important to keep in mind, that participation can include activities children do on their own, not necessarily together with others.” The definition reflects a combined sociological and psychological perspective with emphasis on motivational aspects. Also in Study III, the construct of *activity* was presented as “the child’s execution of acts. It is about general things that the child can do independent of context and involves both single actions, e.g. grasping a pencil and short sequences of actions with a common goal, for example putting on socks, writing with a pencil, eating a sandwich.”

As another contribution to clarify the two constructs, data concerning the distribution across chapters were discussed by Granlund, et al. (Accepted). A number of 207 professionals within child health and educational services were requested to check whether each category in a list of 46, represented activity (a), participation (p), or was not possible to categorize (a/p). The results showed little consensus among the participants for many categories, indicating a lack of clarity in use of the constructs (Figure 3.2). Most categories that were checked as child participation by a majority of the professionals (>50%) belonged to later chapters in the component: Relationships (d7), Major life areas (d8), and Social life (d9), and the single category As-

sisting others from Domestic life (d6). Only two single categories from early chapters were checked as participation by more than 50% of the professionals: Managing one's own behavior (d250) and Conversation-Discussion (d350-d355). In addition, results revealed that the chapters Mobility (d4) and Self-care (d5) were checked as activity. From these results, the second option to structure the relationships between activity and participation (partial overlap) seemed to be the most appropriate. This relationship became further investigated in the dissertation.

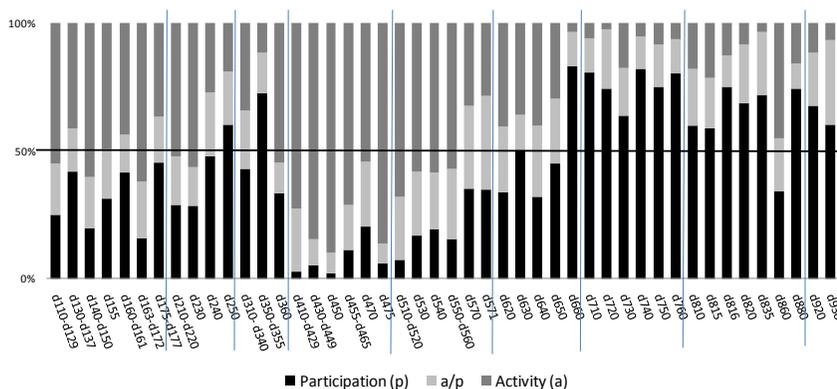


Figure 3.2. Distribution (%) of participation (p) and activity (a) across 46 ICF-CY categories. >50% of responses suggests the category to be understood as either p or a. Adapted from Granlund et al. (Accepted)

The distribution of participation across chapters might be affected by factors such as a children's age and the degree of disability (Granlund, et al., Accepted). Young children or children with profound disabilities may intentionally perform and perceive even a simple action as complex. Thereby it will be characterized as participation even though it for an older child may be characterized as an activity, i.e. an automatically performed action. For example, as long as young children learn to walk or talk, these are emerging skills and the child focuses on the purpose of that particular action. Later on, when walking and talking are automated, the child may have the attention on something else, e.g. planning where to go or discussing with someone while walking.

3.3 QUALIFIERS FOR THE ACTIVITIES AND PARTICIPATION COMPONENT

To specify the extent to which a child's ability differs from an expected or typical state, the ICF-CY recommends the use of qualifiers with values from 0 (no problem) to 4 (complete problem). In the component Activities and Participation, a *capacity* qualifier specifies what a child *can do* independent of context, i.e. the best ability to execute a task or an action in a standardized environment, whereas the *performance* qualifier specifies what a child *does do* in a current environment, i.e. functional skills used in everyday life situations (Msall & Msall, 2007; WHO, 2007). In accordance to McConachie et al. (2006), performance includes what children do in daily life but not necessarily what they want to do in interaction with others or of their own free will. Both capacity and performance might be possible to assess objectively by tests or observations but they do not provide information about how children experience involvement, i.e. the intensity of engagement (WHO, 2007). Neither is it possible to predict children's participation due to degree of impairments; it is rather dependent on how they experience interaction with and support from peers and other people around them (Coward, Saylor, Dingle, & Mainor, 2004; Fusaro, Maspoli, & Vellar, 2009; Meucci, Leonardi, Zibordi, & Nardocci, 2009). When publishing the ICF, it was expected that further research should provide additional qualifiers to allow information reflecting involvement (WHO, 2001). An opportunity qualifier was first suggested by Nordenfeldt (2006) and recently a participation qualifier was suggested by Granlund et al. (Accepted). With three qualifiers available, the interrelation becomes obvious when using an expression borrowed from Kielhofner (2008): capacity is embedded within performance, and the performance is embedded within participation. Besides, participation cannot be seen in isolation but always in terms of a child in a context, i.e. related to a life situation (WHO, 2007).

4 DISABILITY

A paradigm shift in how to define the construct of disability is reflected in the interactive model of ICF-CY. This section describes changed attitudes and perspectives on ‘disability’, and discusses if children with disabilities are by definition disabled.

A paradigm shift in the way disability is defined occurred over the last two decades of the 1900s. Human functioning is no longer seen as exclusively biological, it is rather a product of the interaction between biology and environment making disability neither uniform nor static (Bickenbach, 2010; Bickenbach, et al., 1999). Disabling features vary depending on the complexity of individuals’ shortcomings in interaction with barriers in their environments, i.e. disincentives arising in different physical and social environments. In this respect, disability is changeable, impacted by both intrinsic and extrinsic factors. This interactive approach, with disablement understood as an individual experience, was emphasized by the United Nations when updating the UN Convention on the Rights of Persons with Disabilities (UNCRPWD): ”Disability is a difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors” (UN, 2009). This means a paradigm shift “in attitudes and approaches to persons with disabilities towards viewing persons with disabilities as ‘subjects’ with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society” (www.un.org/disabilities).

In the context of the paradigm shift, the ICF/ICF-CY was introduced as an interactive *health classification* including a bio-psycho-social model of human functioning and disability (WHO, 2007). The predecessor, International Classification of Impairments, Disabilities and Handicaps, ICIDH, was a *handicap classification* including a medical model with a linear progression, referring difficulties at a personal level only and with handicap as an inevitable result of a disease or disorder (WHO, 1980). As such, handicap became an individual identity – ‘he is handicapped’, just as if he was blue-eyed (Baxter, 2007; Grönvik, 2007). Disability as defined by the ICF/ICF-CY means no inevitable disabling terminal point but emphasizes the neutral term participation as a ‘guiding-star’ for functioning.



Figure 4.1. Disability as the umbrella term for the negative aspects of functioning that arise in interaction with barriers in the environment.

The ICF/ICF-CY model defined the construct of disability as an umbrella term covering three aspects: impairments, activity limitations, and participation restrictions affected by barriers in the environment (Figure 4.1), reflecting that understanding disability as an individual problem is insufficient (WHO, 2001, 2007). In Sweden a social-relational understanding of disability is prevalent, meaning that a person’s functioning is related to the impact of a broad variety of physical, human-built, socio-cultural, attitudinal, and political factors (Danermark, 2005; Grönvik, 2007). This includes the interactive approach emphasized by the UN and is recognized in the definition of disability that has been recommended by the Swedish National Board of Health and Welfare: “restrictions that an impairment means for a person in relation to the context” (SoS, 2005).

These national and international definitions of the construct of disability emphasize that a child with impairment is not by definition a disabled child. The construct of a disabled child may bring to mind an understanding that disability is intrinsic to the child in addition to other unique identities (Colver, 2006). However, a child with impairment may not have participation restrictions in all everyday life situations and therefore not be classified as disabled in those situations. Since disability is by definition relational, participation restrictions with need for special support depends on how children deal with everyday life situations in general. In this dissertation, the term ‘children with disabilities’ is chosen to identify children with impairments in addition to special support needs.

5 EVERYDAY LIFE SITUATIONS OF CHILDREN

What do everyday life situations specific for children and youth capture and which impact do they have on children's development and functioning? This section deals with these questions but also with how conditions for participation in everyday life situations differ for children with disabilities.

5.1 THE CONSTRUCT OF EVERYDAY LIFE SITUATION

Everyday life situations are episodes that occur regularly in the natural environments where children usually spend time. The right for children to participate in family life, education, and community events under equal conditions is identified by national laws and policies in all parts of the world (UNESCO, 2000). Everyday life situations include actions with different levels of complexity, context specificity and impact on development and child functioning. These different levels are shown by examples from the literature: bedtime, book reading, education, going to the movies, hand washing, home-related tasks, music lessons, planting flowers, playtime, preparing supper, recreational pursuits, self-care, snack time, and washing the dishes (Coster & Khetani, 2007; Dunst, Bruder, Trivette, & Hamby, 2006; Imms, 2008; McConachie, et al., 2006; Solish, Perry, & Minnes, 2009; Spagnola & Fiese, 2007; Woods, Kashinath, & Goldstein, 2004). Each situation includes sequences of actions performed within everyday contexts (Badley, 2008; Coster & Khetani, 2007). Dressing, for instance, includes reaching, holding, grasping, buttoning, choosing appropriate clothes, putting them on in a sequence, and looking in the mirror to adjust the clothing. Playtime may include actions such as selection of toys, initiating play, relating with peers, making decisions, solving problems, moving around (Sturgess, 2009a). These diverse actions require a wide range of functional skills for children to enable participation in everyday life situations. Related to the ICF-CY, life situations are represented by the life areas included in the component Activities and Participation (Morris, 2009; WHO, 2007). For example, education belongs to Major life areas (d8). Since the life areas range from lower to higher complexity from early to late chapters, an as-

sumption is that life situations correlate with participation mostly in the later chapters of the component.

The construct of everyday life situation implies different levels of formality and meaningfulness. Spagnola and Fiese (2007) talk about *rituals* and *routines* in home settings, both referring to specific, repeated practices that involve at least two family members. Rituals involve symbolic meaning whereas routines could be recognized as parts of daily life in a given culture without implying any special meaning (Coster & Khetani, 2007; Spagnola & Fiese, 2007). Everyday life situations are also talked about as *activities* (Imms, 2008; Law et al., 2006; Solish, et al., 2009), which in home settings are mostly *informal/leisure*, such as reading, resting, watching TV, or playing on the computer. In community settings, however, they mostly refer to *formal/recreational* activities, such as organized sports and lessons, usually with a leader. Formal activities are planned and structured, involving rules or goals. Informal activities, on the other hand, involve limited prior planning and are often self-initiated, for example social activities that include informal engagement with peers (Dunst et al., 2001; Dunst, Bruder, et al., 2006; Dunst, Trivette, Hamby, & Bruder, 2006; Solish, et al., 2009). Most often, everyday life situations provide a combination of planned and unplanned, structured and unstructured episodes.

Everyday life situations may also be seen in the light of their importance for life (McConachie, et al., 2006). There are episodes essential for *survival*, such as eating, excreting and sleeping that are not necessarily tied to a wider context. In contrast, there are episodes, such as participation in leisure activities that are *discretionary*, often tied to the context, and changeable dependent on individual interests and choices. A third category is *education* in which children spend much of their waking time and gain lots of life experiences and skills (McConachie, et al., 2006). In addition, basic episodes including social interactions, spontaneous exploration of the environment, play, and self-directed mobility are highly essential everyday life situations for children, which are important for the development of children's mental, neurological, and communicational functioning. There is no reason to assume that everyday life situations of children with disabilities should differ from those of other children, though the conditions for participation may differ.

Everyday life situations are prerequisites for children's actions and the environments are arenas in which children are active. The construct of everyday

life situation was in Study III in this dissertation presented as “routines that are frequently occurring, comprise sequences of actions, can be accomplished using a variety of tasks, and are goal-directed with meaning for the children”, referring to what occurs regularly in children’s natural environments (Coster & Khetani, 2007; Jette, et al., 2003; Meisels & Atkins-Burnett, 2000). The environment determines what has to be done in a specific everyday life situation. In addition, it regulates the options that are available by having scene-setting roles for children’s actions in addition to providing a variety of contextual factors that influence functioning (Badley, 2008). Since environmental factors constitute either facilitators or barriers, participation may change between everyday life situations and differ from time to time.

5.2 SETTINGS FOR EVERYDAY LIFE SITUATIONS

Home environments have a great impact on children. The UN Convention on the Rights of the Child (UNCRC) has identified families as the natural environments for the growth and well-being of children (UN, 1989, art. 23). According to the bio-ecological model of human development, families constitute the most important micro systems of children (Bronfenbrenner, 1979). To ensure that parents have the capacity to provide nurturing, informed, and attentive environments for their children, they have the right to be afforded necessary protection and assistance (UN, 1989). Throughout childhood, adults provide ‘scaffolds’ for children’s experiences, enabling learning of new skills and positive experiences in home environment may improve a child’s development and functioning right up to adulthood (Bornman & Rose, 2010; Shonkoff & Phillips, 2000; Trevarthen et al., 2003). Interventions for children with disabilities facilitate development if they are designed to meet the needs in the context of families.

Family life offers a wide range of everyday life situations that stimulate multiple aspects of children’s development and provide a feeling of coherence and identity (Sameroff & Fiese, 2000; Wilder, 2008). According to ecocultural theory, family routines and rituals are sensitive to developmental changes (Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996; Weisner & Gallimore, 1994). Therefore, family support and demands of children’s participation in everyday life situations usually adapt in a flexible manner when

children's abilities grow and they can take on a more active role in daily activities. When children get opportunities to help themselves in an active way, they learn about their own capabilities and about how to be independent, which has been established as the primary aspect of well-being in adulthood (Sheldon, Ryan, Deci, & Kasser, 2004). It is important to denote that independence does not necessarily mean being able to live without the support of others but being in control (Bornman & Rose, 2010).

Some everyday life situations in home settings deserve special attention. First, play and games offer opportunities for parents to engage with their children. Depending on age, play is characterized in different ways. It is the most important occupation for young children but in proportion to the whole lifespan it means activities undertaken for its own sake and is an essential everyday life situation beside daily routines such as waking up in the morning, brushing teeth, doing the dishes, washing and cleaning, or visiting relatives (Ginsburg, 2007; Kielhofner et al., 2002). The necessity of play for the growth of cognitive, social, linguistic, emotional, and physical skills is underlined as a human right by the UNCRPWD (UN, 2009). Second, family dinners have been shown affecting a variety of child assets, such as commitment to learning, positive values, and social competencies, but also to decrease family stress (Adolfsson, 2010; Fulkerson et al., 2006). The interactions occurring during mealtimes seem important for how parents support a child's other daily activities, such as school tasks. Finally, rest is a natural element in everyday life that probably needs to be encouraged and looked upon as a leisure activity undertaken in order to relax rather than an ignorable non-activity (Stamm, 2005).

Beside home settings, settings for early care giving such as preschool teach young children about how the world functions and include tasks that provide a variety of foundational skills such as physical, cognitive, and behavioral. In Sweden, half of one-year children went to preschool 2010 and as much as 91.4-98.3% of children aged 2-5 yrs (www.skolverket.se). Preschool teachers estimate that around 17% have special needs but only a quarter of these are identified (Lillvist & Granlund, 2010). Activities in preschool and school are not only academic, they also include mobility, self-care, interpersonal interactions, problem-solving, decision making, and planning (Coster, Mancini, & Ludlow, 1999). If children experience a feeling of belonging when taking part of these diverse activities, their liking

of school may be promoted (Bornman & Rose, 2010) and as emphasized by Csikszentmihalyi and Hunter (2003), children who spend much time in school and other social activities seem happier than those who spend less time there. It also provides children with disabilities opportunities to learn a variety of skills by peer modeling (Cowart, et al., 2004; Sturgess, 2003), which emphasizes the importance for them to participate with other children in different everyday life situations.

5.3 CHILD PARTICIPATION IN EVERYDAY LIFE SITUATIONS

Participation of children does not mean the same as participation of adults. It is dependent on developmental stages, abilities to function independent of adults, and for young children participation is often urged by adults or mandated by the specific everyday life situation (Granlund, et al., Accepted; WHO, 2007). The nature of everyday life situations varies across the stages of infancy, childhood, and adolescence and by age, children can perform increasing parts of tasks such as grooming, dressing, or cooking, but also choose episodes. Having control, doing and being with others, and having fun are elements of participation (Heah, Caste, McGuire, & Law, 2007) reflecting the importance to consider children's choices to promote well-being.

Desires and expectations for participation are mostly the same for children with and without disabilities (Cowart, et al., 2004; Luttrupp & Granlund, 2010). They want to be with peers and exchange experiences with others. However, children with disabilities usually interact less with peers than typically developed children and may need adult support to take part in activities outside home and school settings (Cowart, et al., 2004). It has been established that young children with mild developmental delays usually have peer relationship difficulties, that might cause them problems mastering the social tasks of gaining entry into peer groups, maintaining interaction and resolving conflicts (Guralnick, 2010; Shonkoff & Phillips, 2000). To overcome these difficulties, the impact of social environment plays an important role because children are directly influenced by interactions and activities in their micro environments (Bronfenbrenner & Ceci, 1994). Wachs' descriptions of the systems around the child (2000) introduced the concept *niche*

that clarifies the reciprocal impact of attitudinal considerations and cognitive skills in addition to physical factors. Unfortunately, significant adults around children with disabilities may have low expectations on the children's skills and a tendency to do everything for the child, especially in situations that call for initiatives by the child (Bornman & Rose, 2010; Cardol, De Jong, & Qard, 2002). It might cause learned helplessness in the children, making them develop a passive behavior instead of learning to help themselves in an active way.

The pattern of participation of children with disabilities may differ from that of other children. They are often less engaged, have lower levels of participation in school activities, and are sometimes seen as the least preferred playmates (Almqvist, 2006; Downer, Booren, Lima, Luckner, & Pianta, 2010; Eriksson, 2006; Shonkoff & Phillips, 2000; Sundqvist, 2010). Their experiences of restrictions seem greater in unstructured activities than structured, for example at open spaces such as school playground or at field trips or physical education (Egilson & Traustadóttir, 2009; Leung, Chan, Chung, & Pang, 2011; Luttrupp, 2011; Schenker, Coster, & Parush, 2005). On the other hand, young children with disabilities seem to participate in more varied social leisure activities, though less frequently, perhaps because adults introduce different activities creating opportunities for social involvement (Bedell, Cohn, & Dumas, 2005). Continued involvement, however, seems based on children's preferences (Heah, et al., 2007). Overall, children with disabilities tend to spend more time with adults compared to other children (Guralnick, Connor, Neville, & Hammond, 2006; Imms, 2008; Solish, et al., 2009; Sundqvist, 2010). This difference is most prominent for children with autism spectrum disorder and intellectual disability whereas children with CP seem to manage social activities more independently. The disposition to participate in activities with adults seems related to developmental age and problem behavior causing difficulties in social integration (Bedell, et al., 2005; Majnemer, Shevell, Rosenbaum, Law, & Poulin, 2007). It is likely that the children's understanding of and adaption to everyday demands improve when they achieve support from adults.

The conditions for participation in everyday life situations differ between children with and without disabilities. Within the group of children with disabilities, participation may vary due to type of impairment and abilities but also due to kind of activity, interest, and contextual conditions (Cardol,

et al., 2002; Schenker, et al., 2005). Activities demanding social interactions may take the form of everyday life situations in which many children with disabilities manifest significant difficulties, particularly autism spectrum disorders (King, et al., 2010). Another example is children with CP for whom a major distinguishing factor is that physical impairment and restrictions are influenced by environmental factors including access to objects and events (Colver, 2006). However, also social attitudes may constitute barriers to participation due to a tension between 'normality' and 'disability' (Imms, 2008).

Child participation includes autonomy, self-determination, and an experience of belonging. It is a determinant of well-being and life satisfaction and an important factor defining quality of life (Egilson & Traustadóttir, 2009; Heah, et al., 2007; Larsson Lund, Nordlund, Bernspång, & Lexell, 2007; UNESCO, 2003). In the process of becoming autonomous, children can help create a satisfying way of life if they are capable to stand up for themselves and their rights (Berk, 2009; Carter, Lane, Pierson, & Stang, 2008; Fraser, 2001; Honneth, 2004). This requires that they are seen as partners in social interaction and that they know and apply their own strengths, preferences, interests, and limitations. According to self-determination theory, children's capacity of making own choices emerges across the life span but needs support of significant adults to become involved in a degree that is consistent with their abilities (Deci & Ryan, 2000; Shogren et al., 2008; Wehmeyer & Schalock, 2001). If children with disabilities have the psychological capacity to make choices, they may act autonomously within a social framework even if they are dependent on others, because caregivers can help them compensate for impaired physical conditions (Berk, 2009; Bornman & Rose, 2010; Cardol, et al., 2002).

The degree of participation is affected by child characteristics, tasks, and environment (Egilson & Traustadóttir, 2009; Molin, 2004) and as children learn and grow in joyful situations, adults' consideration to their preferences for participation is significant (Almqvist, Uys, & Sandberg, 2007; Dunst, Trivette, et al., 2006; Law, 2002). Everyday learning that is interest-based may improve children's engagement in other activities, making them prepared for different contingencies and gradually responsible for what happens around them (Beukelman & Miranda, 2005; Dunst, Trivette, et al., 2006; Dunst, Trivette, Raab, & Masiello, 2008). Since children with disabili-

ties most often have lifelong and frequent needs of special learning, exercises, and supported recreation activities, those activities may be stressing for all involved if not experienced motivated (Simeonsson & Bailey, 1990). Promoting participation in everyday life situations enables children to stretch their skills and encourages self-esteem.

5.4 THE ROLE OF FAMILIES

The support from family members or significant others is crucial to promote children's participation in everyday life situations. Consequently, children's development and well-being is dependent on family functioning and parents might need support to reduce stress and obtain everyday functioning (Duis, Summers, & Summers, 1997; Keysor, Jette, Coster, Bettger, & Haley, 2006). Parents' stress may be related to their knowledge about the consequences of impairments and since children demonstrate broad ranges of individual differences, it is difficult for parents to determine whether developmental milestones are within the normal range (Duis, et al., 1997; Shonkoff & Phillips, 2000). Providing parents knowledge about how to explore developmental assets and handle special conditions on their own coping strategies will enhance their feeling of competence and encourage them to become supportive (Fulkerson, et al., 2006; Majnemer, et al., 2007; Ylvén & Granlund, 2009).

How parents structure family life and respond to children's needs have a considerable impact on how the children practice skills, learn to act on their own behalves, and advocate for their own preferences and needs. According to ecocultural theory, families are expected to actively and proactively respond to the circumstances in which they live (Bernheimer & Keogh, 1995; Gallimore, et al., 1996; Weisner & Gallimore, 1994). Adapted family routines can be developmental facilitators, which provide children opportunities to practice everyday tasks repeatedly and with balanced support (Dunst, Bruder, et al., 2006). They provide opportunities for children's own decision-making and structured routines may prevent the development of behavior problems (Shonkoff & Phillips, 2000). Family routines reflect functional aspects of everyday life in a given culture (Bernheimer & Keogh, 1995; Coster & Khetani, 2007; Spagnola & Fiese, 2007). They vary and change over time due to children's age, family conditions such as available

resources, time of the year, interests, and a wide range of other internal and external variables.

Some parents may need professional help to guide children into an independent adulthood. Such help is about giving adequate support, having the children's preferences honored, and providing opportunities to develop skills such as choice making. This process starts in early ages and impacts children's abilities to make choices later in life (Brotherson, Cook, Erwin, & Weigel, 2008). For example if adults select children's materials, children become less engaged compared with selecting toys and initiating play themselves. If parents learn how to use frequent situations in the home environment as facilitating scene setters for their child's participation (Badley, 2008), the child may experience control and develop into a self-determined adult.

6 SERVICES FOR CHILDREN WITH DISABILITIES

Children with disabilities may need support throughout the lifespan. A central question is: How can professionals provide interventions that over time make a meaningful difference in the children's everyday life situations? This section will deal with this question in addition to briefly present the rights of children and the Swedish system of habilitation services.

6.1 REGULATIONS

The rights of children and youth with disabilities to be heard and supported are established by international regulatory frameworks as well as national ones. UNCRPWD establishes that children with disabilities should be able to participate on equal basis with others in all life areas and that they have the right to express their views freely on all matters affecting them (art. 7) (UN, 2009). UNCRC adds that children have right to seek, receive, and impart information and ideas of all kinds (art. 13), that the best interests of the child should be a primary consideration (art. 3), and that children with disabilities should enjoy a decent life and furthermore have access to health care services of high standard (art. 23-24) (UN, 1989). Similar principles are expressed by the goal of Swedish disability policy that is to ensure people with disabilities power and influence over their everyday lives and good health care on equal terms (Table 6.1). The laws pay attention to collaboration with individuals for intervention planning whereas the disability policy points out the importance of the individuals' freedom of choice. All documents establish the need to support participation in society, i.e. to provide people with disabilities a life equal to others. Concerning children, collaboration involves parents since they advocate their children's lack of autonomy (Bischofberger, Dahlgvist, & Elinder, 1991; Henriksson, 1992; Regeringskansliet, 1995).

Attitudes to children with disabilities have changed over time, primarily depending on paradigm shifts in attitudes to people with disabilities in general. In a historical perspective, they have been seen as 'invalids', i.e. without value, and not fitting into society (Kudlick, 2003; Stiker, 1999; Thyberg,

2004). Until the middle of 1900, persons with intellectual disabilities were seen as ‘objects’ and, placed at institutions, they were separated from the ordinary social life, which resulted in social deprivation and taught helplessness (Ericsson, 2005; Förhammar, 2007; Grunewald, 2003; Grunewald & Bakk, 2004; Näslund, 2007). Altered attitudes during the 1900s made people with disabilities finally seen as ‘subjects’ and recognized as citizens with equal value and democratic rights. Normalization with focus on normal daily routines became a core ideological principle (Nirje, 2003). The intention today is equal participation, opportunities, rights, and obligations.

Table 6.1 *Swedish regulations relating to health care, support, and services for children with disabilities*

Document	Involvement in decisions	Participation in everyday life	Comment
NATIONAL LAW The Health and Medical Services Act (HSL) (Regeringskansliet, 2002)	Duty to plan interventions in consultation with the individual concerned.		The law covers all people; aims to assure the entire population good health and care on equal terms.
NATIONAL LAW Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) (Regeringskansliet, 1994)	Duty to draw up an individual plan in consultation with the person concerned.	Promote equality in living conditions and full participation in the life of the community by providing support.	The law covers people with extensive needs.
NATIONAL DISABILITY POLICY (Regeringskansliet, 2004)	Policy to provide children and young people possibilities to live independent lives and to make their own decisions about their lives.	Principle of universal equality and equal rights; particular focus on obstacles to full participation in society. Disability issues are to be considered in all areas of society.	Decentralization, integration and normalization are core ideological principles that emphasize the individual’s freedom of choice and influence.

6.2 SWEDISH HABILITATION SERVICES

Child and youth habilitation services in Sweden are county council organizations supporting children and young people aged 0-17 years with disabilities, their families, and other networks. The services are needs based rather than rights based, such as in for example the U.S. and Portugal where interventions require eligibility (Bickenbach, 2009; Björck-Åkesson & Granlund, 2005). The construct of *habilitation* focuses on acquiring skills whereas *rehabilitation* focuses on regaining lost skills. Despite this slight difference, the objective of services is consistent: “A process to reach and maintain individual’s optimal levels within various functional areas and to attain independence and self-determination” (WHO, 2010). The birth of Swedish habilitation services can be set to the 1950s (Bille & Olow, 1999; Thyberg, 2004). During the years, the target group has changed to include children with a wide range of disabilities categorized as mobility, behavioral, intellectual, and multiple disabilities.

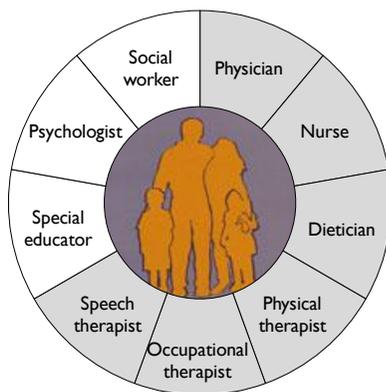


Figure 6.1. Disciplines in Swedish habilitation teams. In addition, recreational counseling specialist might be apparent. Grey marked disciplines belong to the medical competence.

Interdisciplinary habilitation teams include social, psychological, pedagogical, and medical competencies with a marked preponderance of the latter (Figure 6.1) (Granat, et al., 2002; Habiliteringschefer, 2009; Åman, 2006). The services are family centered, i.e. families are involved in intervention planning (Björck-Åkesson & Granlund, 2005; Turnbull, et al., 2007; Ylvén

& Granlund, 2009). Their involvement is fundamental, because professionals and families may differ in concerns and focus on different outcomes (Eriksson, 2006; Stenhammar, 2010; Thomas-Stonell, et al., 2009). For example, while children want to be active, parents might bother about their general functioning in everyday life situations, and professionals focus on discipline specific functions and abilities. The family-centered approach also addresses needs of families due to the importance of families for children's development and well-being.

Family centered service has meant a shift from an expert service model to a consultative model in which professionals' expertise is used for support rather than for direct services (Buisse & Wesley, 2005). Professionals' task has been to guide children and parents, considering individual children's everyday life situations, successes and failures, wishes and conditions. Aiming to make a change in children's lives that they experience as meaningful, the consultative model requires an interdisciplinary collaboration strategy across medical, psychological, social, and pedagogical perspectives (Msall & Msall, 2007; Msall, Tremont, & Ottenbacher, 2001; Simeonsson, 2006). In the process of developing such a strategy, the ICF-CY may act as a road-map (Martinuzzi et al., 2010). However, it presupposes that the classification is accepted as a common reference and that the different disciplines may agree on common over-arching goals for discipline specific interventions. At present time, the ICF-CY perspective of child functioning is familiar but not necessarily implemented as interdisciplinary practices (Adolfsson & Granlund, 2008; Pless, Ibragimova, Adolfsson, Björck-Åkesson, & Granlund, 2009). Besides, Mellin and Winton (2003) found that interdisciplinary collaboration may only engage professionals a few hours per week. This suggests a need to further develop interdisciplinary teamwork with professionals geared towards common goals for children and their families.

6.3 INDIVIDUALIZED PLANNING OF INTERVENTIONS

The overarching aim for habilitation services is to promote well-being and participation in everyday life situations (Habiliteringschefer, 2009). Professional support in natural environments is a unique task compared with oth-

er health interventions and influences both interdisciplinary methods and the purpose of interventions. The task places special demands on motivating children and parents to interventions because a ‘sense of coherence’ may make them manage everyday demands and adversities with a preserved feeling of well-being (Antonovsky, 2005). The chance that children will be motivated is likely to increase if interventions are discussed in relation to participation which for a child means being active (Eriksson & Granlund, 2004a). Children learn through ‘doing’ and the environments where they spend their daily lives play a significant role for development as scene setters for engaging experiences and opportunities for interventions in everyday life situations (Badley, 2008; Berk, 2009; Dunst, et al., 2001; Dunst, Trivette, et al., 2006). Besides, motivation is fuel that generates and directs energy (Almqvist, et al., 2007; Bornman & Rose, 2010). Therefore, interventions will be effective and promote children’s drive for new experiences if they match their developmental level and are experienced joyful, making the children interested, open-minded, and willing to make efforts.

The scope of assessing child functioning is to understand how children deal with their everyday life situations, i.e. what they want, what they are able to do, and what they actually do (Bornman & Rose, 2010). Thus, involving children and parents as active parts in assessment adds important information to professionals’ findings of tests and observations (Bagnato, Neisworth, & Pretti-Frontczak, 2010; Msall, et al., 2001). Children and parents provide information about everyday functioning, daily routines, and physical as well as social environments; core information for professionals to understand their everyday problems. Assessment is of specific importance during transitional phases that occur throughout the childhood and adolescence, leading to reorientations in how a child relates to the environment (Shonkoff & Phillips, 2000). By applying the multidimensional ICF-CY as an innovative means for professionals to achieve shared information, they might explore changes in functioning that are not easily highlighted by traditional dimension-specific assessment measures (Carlson, Benson, & Oakland, 2010; Florian, et al., 2006; Rentsch, et al., 2003; Simeonsson, et al., 2010; WHO, 2007). The classification may guide interdisciplinary teams in drawing functional profiles and describe children’s everyday functioning in “a sort of 360° fish-eye perspective” (Bonanni et al., 2009; Fusaro, et al., 2009; Leonardi & Martinuzzi, 2009) in order to en-

hance understanding of how an individual child deals with various everyday life situations during different phases.

The challenge to plan and carry out individualized interventions requires a living dialogue with consideration to a variety of personal and environmental factors (Granat, et al., 2002; Michelsen, 2010). By that, parents may feel that professionals take into account all various demands placed upon them and consider families in a broad context of their lives (Bernheimer & Keogh, 1995; Brotherson, 2001; Brotherson, et al., 2008). Dunst et al. (2006) found that encouraging parents to use everyday life situations as sources of intervention opportunities was associated with benefits both for children's progress and for parents' feeling of control, parenting competence, and well-being. Contrary, professionals' implementation of interventions in home settings was associated with limited benefits and decreased well-being. So did high intensity of services provided to a child; it seemed stressful and decreased parents' feeling of control (Dunst, Hamby, & Brookfield, 2007). This emphasizes the importance to consider *how* professionals interact with families rather than *how much*.

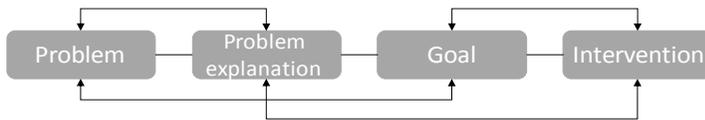


Figure 6.2. Problem solving model for intervention processes in habilitation services.

Habilitation is mostly a long lasting, collaborative problem solving process with many stakeholders involved (Figure 6.2) (Björck-Åkesson & Granlund, 2002). Apart from parents, there may be other caregivers or family members, teachers, personal assistants, and administrators. As established by the UNCRC, also the children themselves have the right to be involved in the process to a degree that suits their maturity, given opportunities to express their own preferences and needs and to make own choices. Children's engagement in intervention planning offers natural opportunities to improve their critical skills and promote self-determination, but also to guide parents in how to introduce or moderate self-determination in daily routines (Carter, et al., 2008; Molin, 2004). Involving children in intervention plan-

ning affirm that professionals prioritize the development of self-determination by encouraging them to stand up for themselves (Carter, et al., 2008; Turnbull, Turnbull, Erwin, & Soodak, 2006). It might make professionals utilize an asset-based approach by capitalizing strengths and address that barriers are not the end of the road but something to overcome (Bornman & Rose, 2010; Carlson, et al., 2010; Ebersöhn & Eloff, 2006). Most likely, this approach enhances motivation and makes interventions sustainable by focusing on desirable outcomes that are directly related to participation.

To make collaboration work, professionals are responsible for empowering children and parents and for creating cooperative relationships with the networks (Dunst, Trivette, & LaPointe, 2000). Since stakeholders' perspectives of outcomes do not always match, one challenge for professionals is to create a balance between interventions (Gibson et al., 2009; McCormack, et al., 2010; Neander & Skott, 2008; Thomas-Stonell, et al., 2009; Vargus-Adams & Martin, 2011; Wiart, Ray, Darrah, & Magill-Evans, 2010; Winton, 1996). Over time, parents tend to take greater initiatives and the professionals can adopt a more passive role (Ylvén & Granlund, 2009). Brown and Gordon (2004) characterize power relationships in terms of two images: 1) muscle, i.e. who controls the decision-making, and 2) voice, i.e. how much of the insider's versus the outsider's perspective is revealed. Based on these images, professionals are the outsiders that initially have more muscle and voice than the families. As such, they must be aware of their controlling position, gradually transfer power to the parents and children, and encourage them to make their voices heard to avoid misconstructions.

7 AIMS OF THE DISSERTATION

The overall aim of the present dissertation was to investigate how habilitation professionals perceive the utility of the ICF-CY in clinical work. It was also to identify everyday life situations specific for children and youth aged 0-17 years as a basis for brief code sets for child participation in everyday life situations aiming to guide individualized assessment and intervention planning. By that, the findings will guide further development of an interdisciplinary participation-focused screening tool consisting of ICF-CY based code sets for self- or proxy-report. Since the ICF-CY constitutes a recently developed conceptual framework expected useful for the new tool, professionals' experiences were important to consider for the planning.

SPECIFIC AIMS OF EACH STUDY

- I. To explore how professionals in interdisciplinary teams perceived the implementation of the ICF-CY in Swedish habilitation services.
- II. To identify common everyday life situations of children and youth based on measures of participation.
- III. To identify professionals' views of everyday life situations of importance for children and to explore how the construct of Life situation correlate with the construct of Participation.
- IV. To develop a set of specific everyday life situations to be included in a screening tool for children and youth aged 0-17 years by integrating data from several studies providing different perspectives on everyday life situations.

8 METHODOLOGICAL CONSIDERATIONS

This dissertation with a primarily qualitative approach includes four studies conducted with different methods. In this section, methodological issues will be presented and discussed.

8.1 RESEARCH DESIGN

The research had a primarily qualitative approach with a multi-method design, including descriptive and comparative content analyses (Creswell, 2009; Morse, 2003). A qualitative approach was chosen because the dissertation aimed to achieve an understanding of two phenomena: 1) professionals' experiences of applying the ICF-CY in daily work and 2) children's most important everyday life situations.

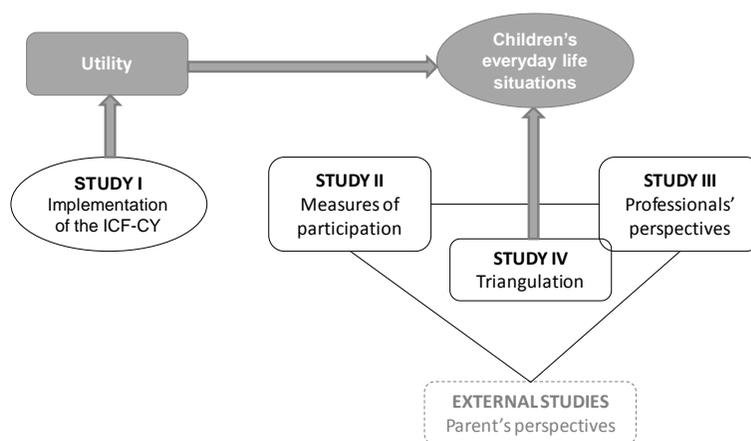


Figure 8.1. The studies of the dissertation.

The design in Study I was descriptive and longitudinal, exploring utility of the ICF-CY, i.e. how an implementation in Swedish habilitation services was perceived. One purpose was to decide whether it was appropriate to continue the work in these terms (Figure 8.1). Studies II-IV were interrelat-

ed and based on the previous findings, focusing on the overall research problem to explore children's most common everyday life situations. Study II was descriptive, extracting information from selected measures of participation. Mixed methods design bridged studies III-IV aiming to integrate information from various sources, i.e. professionals, measures, and parents. In Study IV, a final triangulation included data from Study II, III, three external studies. All together six data collections were integrated and prioritized equal, synthesizing sets of everyday life situations for children at different age groups.

In Study I, inductive examination of professional statements about the utility of the ICF-CY provided a general understanding of how the implementation of the classification influenced habilitation work. The qualitative content analysis, inspired by Graneheim and Lundman (2004), allowed a combination of manifest and latent analyses that resulted in categories telling *what* the influences captured and themes telling *how* professionals' work was influenced.

In Study II-IV, analyses were conducted by using the ICF-CY as the predetermined conceptual basis, taking advantage of the ability to link information to classification codes assuming that everyday life situation are represented by the life areas included in the ICF-CY component Activities and Participation. Mixed methods design was chosen because it allowed both inductive and pre-determined methods, open- and close-ended questions, multiple forms of data, and text and statistical analysis (Creswell, 1998, 2009; Morse, 2003; Teddlie & Tashakkori, 2003). To enhance understanding of children's everyday life situations, several data sets included information collected with various sampling strategies, different sources, and with the perspectives of research and professionals, by that providing complementary result. In this dissertation, a *concurrent* mixed methods design was used. The final triangulation provided integration of empirical data from external data sets adding the perspectives of parents, intending to provide corroborating evidence to strengthen the inference quality.

8.2 METHODS

8.2.1 SOURCES

Study I included information from all members of interdisciplinary habilitation teams. Study II-IV captured information from multiple sources aimed to ensure a broad representation of opinions (Algurén, 2010; Cieza, Ewert, et al., 2004). In Study II, research perspectives were sought in selected validity studies of measures for children and youth with disabilities. In Study III, clinical data came from professionals working with children in different organizations in various parts of the world. In Study IV, ‘user-data’ were integrated, represented by children’s networks including parents.

8.2.2 STUDY SAMPLES

In Study I and III, strategic samples and samples of convenience were used including participants with experience of children with or without disabilities. The strategy was to explore a wide range of child related experiences by selecting a multi-various and interdisciplinary sample including professionals and graduate students in child health care (habilitation services included) and education in different countries (Table 8.1).

Table 8.1 *Samples in Study I and III.*

Data collection		Child health care	Education	Students	Others	TOTAL	Sweden	Portugal/ other EU	USA/ Canada
Study I	In-service training	151				151	151		
	1 year after training	113				113	113		
	2½ years after training	16				16	16		
Study III	Open-ended question	174	41	21	61	297	228	18	51
	Questionnaire	84	41	21	61	207	138	18	51

Convenience was achieved by recruiting participants from the nearby Uppsala-Örebro region and Jönköping where habilitation directors had asked to be involved in research. In Study III, participants were also recruited in conjunction with other research or educational activities, for example graduate courses and the Transatlantic Consortium on Early Childhood Intervention: Advancement of Policy and Practice (<http://www.atlantis-eci.net/start.asp>).

8.2.3 MATERIALS

The materials used for data collections associated with this primarily qualitative dissertation included open-ended questions, a questionnaire on constructs, and protocols, all specifically developed for this purpose. In addition, external data sets were used.

OPEN-ENDED QUESTIONS

One *oral open-ended question* was used in Study I: ‘How can you use/have you used what you learned during the in-service training in your daily work?’. Groups of participants answered the question at two time-points: 1) during in-service training, i.e. when professionals learned about the ICF-CY, and 2) two-and-half years later, i.e. when representatives reported on the use of the classification.

An *Adapted PMI-Form* including five open-ended questions was used during in-service training in Study I. Three questions intended to make participants reflect on what they learned from different perspectives and in ways that they were not necessarily used to: ‘What are the good points?’ (Plus) ‘What are the bad points?’ (Minus) ‘What is Interesting?’. The original PMI-Form was developed by the American psychologist De Bono in 1985 as part of a lateral thinking concept for change of perceptions (McFadzean, 2001; Portmann & Easterbrook, 1992). Because the three questions were unspecified, the PMI-Form was supplemented with two questions encouraging participants to write comments about the in-service training and overall opinions about the ICF-CY.

A *questionnaire* with three open-ended questions was used at two time-points in Study I. One and two-and-half years after in-service training, i.e. when professionals tried and used the ICF-CY, participants were requested to

answer three questions: 1) 'Did the in-service training generate new ideas?', 2) 'Have you used what you learned?', and 3) 'Has the ICF-CY influenced your way of working with habilitation planning?'. Response alternatives were Yes or No, with options to write comments. The specified question about habilitation planning was decided since professionals during in-service training had expected the ICF-CY to be useful for this purpose.

One *written open-ended question* was used in Study III: 'Please list at least five everyday life situations you feel are important to consider in assessment. Identify the age group on which you are basing your answers'. It was followed by seven empty lines. The task was introduced as 'Everyday life comprises different situations in which children function within a certain context (e.g. mealtimes, sleep, playing in the schoolyard)'. In order to assess child functioning, a useful approach is to define these everyday life situations of children'. The question was presented at the beginning of two different questionnaires aiming to evaluate in-service training on the ICF-CY.

PROTOCOLS

Two *protocols* were used in Study II:

- I. 'Appraisal of Full Text Articles: Review - Assessment Tools for Children and Youth with Disabilities' used to apply inclusion/ exclusion criteria during the process extracting articles (see Appendix 1).
- II. 'Appraisal of Assessment Tools for Children and Youth with Disabilities' used to apply inclusion/exclusion criteria during the process identifying measures in selected articles. In the protocol, content in excluded measures were noted in relation to the ICF-CY components and chapters (see Appendix 2).

The protocols were developed on the basis of the Adapted Auperin's Rating Scale (Auperin, Pignon, & Poynard, 1997) and peer-reviewed during the development process.

QUESTIONNAIRE

A *questionnaire on constructs* 'Assessing Child Functioning in Everyday Life Situations' and a consent request were constructed for use in Study III (see Appendix 3). The aim was to collect information on participant's percep-

tions of the constructs of activity, participation, and life situation related to ICF-CY 2nd level categories in the component Activities and Participation.

To reduce the number of 2nd level categories in the component from 132 to 46, categories with supplementing content were merged to ICF-CY blocks, e.g. Purposeful sensory experiences (d110-d129) or to combinations of related categories, e.g. Learning to read, write, and calculate (d140- d150). To make the categories understandable, titles were elucidated by short descriptions taken from the ICF-CY, for example Acquisition of goods and services, e.g. shopping (d620) or Managing one's own behavior, i.e. carrying actions in a consistent manner in response to new situations, persons or experiences (d250). All categories titled 'other specified' or 'unspecified' were excluded and also 13 categories that did not represent typical everyday life situations of children 0-17 years, for example Acquiring a place to live (d610) and Remunerative employment (d850). Unfortunately, one category was missing by accident: Writing messages (d345).

To enable wide spread use, the questionnaire was developed in Swedish and English in parallel. Both versions were peer-reviewed before use. In the questionnaire, the ICF-CY codes were hidden and the categories sorted by text in alphabetical order. The key constructs were defined as follows:

- *Activity* is the child's execution of acts. It is about general things that the child can do independent of context. It involves both single actions, e.g. grasping a pencil and short sequences of actions with a common goal, for example putting on socks, writing with a pencil, eating a sandwich.
- *Participation* is the child's involvement in a life situation. It reflects children's choice to do activities in specific everyday life situations. It also reflects the extent to which the child actively engages in the purposeful activities of daily life in different contexts, for example playing in the school yard with friends or eating with family.
- *Everyday life situations* are sequences of actions that are functional within everyday contexts and directed towards goals that are meaningful for the child. For example, dressing comprises actions to choose appropriate clothes, to put them on in a natural order, and to look in the mirror to adjust the clothing. Another example is mealtime, compris-

ing actions like washing hands, sitting at the table, eating, and conversing.

Participants were requested to review categories in three steps to check whether they 1) represented activity, participation, or activity/participation, i.e. indefinable; 2) represented an everyday life situation or not; and 3) whether a checked everyday life situation was perceived important to assess. At the end of the questionnaire, demographic information was asked for. The analyses were simplified by the ICF-CY codes, enabling that answers in the two versions could be easily compared. Findings concerning the distribution of activity vs participation were presented elsewhere (Granlund, et al., Accepted).

EXTERNAL DATA SETS

Three *external data* sets were used in Study IV:

A Swedish study aiming to investigate networks' spontaneous perceptions of everyday activities for children and youth with severe disabilities (Möller, Westerberg, & Adolfsson, In prep.). The set of activities should be used to prioritize activities for interventions purposing to increase participation and independence in everyday life. Participants were seven networks of children aged 10-19 years, including 61 persons: parents (8), personal assistants (11), teachers (9), special educators (5), headmasters (7), counselors (4), administrators for development assistance (4), and interdisciplinary habilitation professionals (13). Data including notations of 249 everyday activities in school and home settings were linked to the ICF-CY. Everyday activities were related primarily to three ICF-CY chapters: Self-care (d5), Major life areas (d8), and Community life (d9).

A USA/Canadian study, aiming to develop a parent-report measure for population research (Participation and Environment Measure for Children and Youth, PEM-CY), investigated what types of activities parents perceive to be important for their school-aged children in home, school, and community (Bedell, Khetani, Cousins, Coster, & Law, 2011; Coster et al., Submitted). Focus groups interviews were conducted with 42 parents of children with (17) or without (25) disabilities. The parents were primarily white (37) with college education or higher (39). The researchers linked 25

comprehensive items to the ICF-CY, revealing 40 ICF-CY codes (Coster, et al., Submitted). To ensure comparable linkage, the author of this dissertation recoded items and examples using the linking rules and the additional rules that are presented below (heading Linking process). This linkage extended the original 40 ICF-CY codes to 45. Discrepancies concerned Socialization (d9) vs Relationships (d7), School-related activities (d8) vs Recreation and leisure (d9), and whether homework and school preparations are related to School education (d820).

A South African study aimed to develop an interview schedule focusing on children's learning opportunities within the family context in low income areas (Balton, 2009). To compile a list of activities, the American survey *Parent Survey of Home and Family Experience* (Dunst & Bruder, 1999a, 1999b) was revised by three speech therapy assistants in Soweto and thereafter processed in three steps in focus groups interviews with 15 parents or caregivers of typically developing children aged 3-5:11 years, who attended an African Self-Help Association preschool in Soweto. Participants were selected through a stratified sampling procedure, which accounted for the age, gender and development of the children. Fifty activity settings for preschool children were identified by Balton (2009). For this dissertation, the activities were linked to the ICF-CY by six researchers, among them the author of the present dissertation, as a collaborative task between the Swedish research environment CHILD (Children-Health-Intervention-Learning-Development) at Jönköping and Mälardalen Universities and the South African research group CAAC (Centre Augmentative and Alternative Communication) at University of Pretoria.

8.2.4 ANALYSES

To explore everyday life situations and achieve an understanding of professionals' perceptions of the use of the ICF-CY in clinical work, qualitative analyses were primarily used, supplemented with descriptive statistics in order to quantify information gathered with qualitative methods.

In Study I, a combination of manifest and latent content analyses was used with reference to Graneheim and Lundman (2004). Because these authors presented an overview of important constructs related to the procedure, it

provided a basis to ensure a consistent use of constructs and a model for the process of qualitative analysis.

In Study II-IV, the ICF-CY worked as a structure for manifest content analyses and comparison of information. Linking rules by Cieza et al. (2005) were used supplemented by *Guidelines for coding ICF* presented in the ICF-CY, annex 2 (WHO, 2007).

8.3 METHODOLOGICAL DISCUSSION

8.3.1 PROFESSIONALS' STATEMENTS

In this dissertation, Study I was part of a larger project purposing to analyze the utility of the ICF-CY in habilitation services (Björck-Åkesson et al., 2010; Klang, Pless, Adolfsson, Granlund, & Björck-Åkesson, Accepted; Pless, et al., 2009). Because data collected one year after in-service training showed that professionals tried to use the framework but had not yet implemented it in daily routines, a third data collection was decided. This allowed investigation over a longer time, however with the risk that the small group of representatives at the third time point affected the statements. They reported on *how the ICF-CY was used* more than *how they perceived the utility of the ICF-CY*, perhaps because they felt like just 'representatives' that would report on practical implications.

8.3.2 PREPARATION FOR CODE SETS

The present dissertation includes preparation for a future screening tool with code sets for everyday life situations. Three sources were used to identify common everyday life situations: content in measures of participation, opinions of professionals, and opinions of parents. Compared with four perspectives that have been general in the development of core sets for health conditions (Cieza, Ewert, et al., 2004), these sources cover most of the perspectives, however excluding the child perspective (Table 8.2). Related to everyday life situations, parents may serve as experts knowing most about what happens in children's natural environments, but also as users because they belong to the target group for habilitation services. Professionals serve as experts with knowledge about conditions important for

everyday functioning in general and as clinicians working with children with disabilities.

Table 8.2 *Perspectives represented in the development process of code sets compared with core sets. Gray marked boxes are included in the present research*

Core sets for health conditions	Code sets for participation in everyday life situations	
Research	Research	Content in measures
Expert	Expert	Parents and professionals
Clinicians	Clinicians	Professionals
Patients	Users	Parents and children

One advantage that is expected by engaging professionals is that it may improve face validity of code sets. Parents were not directly engaged in the current studies because other ongoing studies that included parents were known in the planning phase and expected to provide data. Integration of professionals' and parents' perspectives is essential. The professional perspective involves the risk that data are marked by their discipline-specific roles. Consequently, the parental perspective involves the risk of a narrow, family-oriented perspective. Besides, experiences about children with and without disabilities and with cultural diversity are essential. To meet these necessities, this work included data from professionals and parents with various child experiences in different cultural contexts.

8.3.3 ASSIGNING CONTENT TO THE ICF-CY

In Study II-IV, assigning data about everyday life situations to the ICF-CY made it possible to view the content in different data sets from a common base. Items in measures, responses to an open-ended question, and data in external data sets were linked to ICF-CY codes on 1st and 2nd level consistent with existing linking rules, although not without problems (Cieza et al., 2005). One concern was that the construct of life situation does not have an explicit place in the ICF-CY model and was therefore assumed related to categories classified as participation. Another concern was that the construct of participation is not clearly distinguished from activity. To overcome these ambiguities, an extra step was added in Study III aiming to explore which chapters in the Activities and Participation component that include everyday life situations.

The ICF-CY was consistently used in exchange for the ICF and therefore, two measures were recoded (PEDI and COPM). This procedure showed the relevance of using the child version since items were linked to categories that did not exist in the ICF, for example Engagement in Play (d880) and Indicating need for urination and defecation (d53000 and d53010) (Stamm, Cieza, Machold, Smolen, & Stucki, 2004; Östensjö, Bjorbäkmo, Brogren Carlberg, & Völlestad, 2006).

Because items and statements at issue for linkage were short and limited, they could be divided into meaningful concepts as described by Cieza et al. (2005). These meaningful concepts became comparable when transformed into counts by manifest linkages as also reported by other researchers (Cieza & Stucki, 2005; Klang, et al., Accepted; Ogonowski, Kronk, Rice, & Feldman, 2004; Schiariti, Fayed, Cieza, Klassen, & O'donnell, 2010; Stamm, et al., 2004; Ståhl, Granlund, Gare-Andersson, & Enskär, 2010; Östensjö, et al., 2006). The linkage procedure was somewhat problematic. For example, tasks related to what happens during a school day – are they to be linked to School education (d820) or is it relevant to link them to the more specific category such as play (d880) or dressing (d540)? With regard to play, the word exists in two categories, as a Major life area (d880) and as Recreation and leisure (d920). These and other concerns are discussed below.

The importance to agree on how to conduct the content analysis was noticed. Researchers' different backgrounds made them tackle the analyses differently. It pointed to a probable use of latent content analysis, which generated low inter-rater agreement, whereas guiding a manifest analysis provided increased agreement. Some examples of contradictory linkages are:

- 'Errands' was linked manifest to Shopping (d6200) or interpreted as the underlying features of the execution of running errands, such as Undertaking single or multiple tasks (d210-d220).
- 'Puts away own clothes' was linked manifest to Doing housework (d640) or interpreted as Completing a simple task (d2104).

The relevance of defining the aim for each data analysis, as stressed in the linking rules, was noticed (Cieza, et al., 2005). Since this dissertation aimed to identify everyday life situations in relation to life areas within the ICF-CY component Activities and Participation, a single word such as nutrition

was looked upon as Eating (d550) rather than the product Food (e1100). Linkages were also affected by the target group *children* compared with *adults*. Therefore, Exercise was linked to Sports (d9201) whereas for adults and depending on the situation, it could have been assigned to Looking after one's health (d570).

During the linkage procedures, special considerations were given to certain expressions, for example the overall term ADL (Activities of Daily Living). According to Whiteneck and Dijkers (2009), classical ADL's are washing, caring for body parts, toileting, dressing, eating, and drinking; all categories linkable to the ICF-CY chapter Self-care (d5). However, ADL might be linked to more chapters and in the ADL taxonomy, developed for occupational therapists as a guide for assessment, it includes Self-care (d5), Domestic life (d6), Mobility (d4), and Communication (d3) (Sonn, Törnquist, & Svensson, 1999). When analyzing participants' proposals as a whole, ADL seemed primarily involve Self-care.

Another activity that brought problem was Sleep because it is not included in the ICF-CY component Activities and Participation but described in the component Body functions (b134). Still, sleep might be part of the life areas in the ICF-CY because it is both related to an individual's survival and an essential family routine for young children (McConachie, et al., 2006; Spagnola & Fiese, 2007). Regarding sleep as an activity, it was first looked upon as a daily routine and linked to General tasks and demands (d2). However, sleeping as an activity including preparing to go to bed for a whole night sleep probably means more than the general aspects of carrying out daily routines. Since it might be about Looking after one's wellbeing, i.e. close to Looking after one's health (d570), linkage to a close category within Self-care (d569) seemed suitable whereas 'rest' could be looked upon as an informal, relaxing leisure activity (d920) (Stamm, et al., 2004).

Some obstacles that required special considerations emerged during the linking processes. The obstacles primarily concerned how to link activities related to Play (d880) vs Recreation and leisure (d920), School education (d820) vs School related activities (d835), Learning (d1) vs School education (d820), and Behavior. They also concerned contextual issues (references to setting or extent of support) and organizational issue (different versions of the same measure). For instance, the original coding of the PEDI Functional Skills Scale (Östensjö, et al., 2006) reported a frequent use of linkages

to the component environmental factors that was understood as the context of requested functions, i.e. extent of support. In Study II these were considered as response options. Additional linking rules were set up to overcome as many obstacles as possible and to ensure consistent linkage:

- All linkages were based on the ICF-CY due to the extended content in comparison with the ICF.
- Unspecified constructs were assigned codes on ICF-CY 1st level, e.g. Learning (d1), Communicating (d3), or Doing work at home (d6).
- The unspecified construct of ADL was assigned to the ICF-CY 1st level Self-Care (d5).
- Unspecified responses expressed as 'hygiene' were related to a group of 2nd level categories within Self-care (d510-d530)
- The unspecified response socialization was linked to Community life (d9) whereas interaction with persons, such as family or peers, was linked to Relationships (d7).
- Sleep was linked to Self-Care (d569) whereas Rest and relating concepts were linked to Recreation and leisure (d920).
- The linkage of Behavior was based on the purpose of each individual item. It was looked upon as a body function (b125, b126) alternatively as an activity manifesting itself as a social behavior (d240, d250).
- Similar items occurring in measures with different versions for different age groups were assigned only one code.
- All items related to food, meals or eating/drinking were linked to Eating and drinking (d550-d560).
- Activities taking place during school time were seen as school education with reference to the definition of category d8201 (Maintaining educational programme).
- The concepts play and games were separated:
- Solitary or shared cooperative, developmental play without special rules was linked to d880 (Engagement in play).
- Play for amusement, engagement in games with rules, and competitive play such as playing cards or chess performed during leisure time was linked to d920 (Recreation and leisure).
- References to contexts were not considered, for example Play on playground.

These additional rules may be useful for future studies.

9 ETHICAL CONSIDERATIONS

The four ethical principles including information, consent, confidentiality, and use that are set by HSFR (Humanistiska- och Samhällsvetenskapliga rådet [Humanities and Social Council]) (HSFR, 1990) were deemed to be satisfied as described below. None of the studies in this dissertation involved risks for human subjects. Participants were asked about general opinions, not about any personal issues, the information about participants in studies I and III was limited to demographics; and data were analyzed on group level. Participants were informed by word of mouth as well as in writing, and participation was voluntary. In Study I, informed consent was obtained from directors for all professionals at a time and in Study III informed consent was assumed when participants decided to give their opinions and complete the questionnaire. Information about participants will not be left out or used for any other purposes than research.

Study I was part of a broader project that was approved by the ethics committee of the Faculty of Medicine at the University of Uppsala, Sweden (no. 2005/221). Ethical considerations were carefully assessed for this project by the Central Ethical Review Board in addition to the regional authority concluding that approval was not needed in accordance to the Swedish Act on Ethical Review of Research involving humans (2003:460). Study II did not involve any human subjects. Study III-IV was approved by the Institutional Review Board (IRB) at the University of North Carolina at Chapel Hill (no. 09-2013).

10 SUMMARY OF STUDIES

STUDY I. Exploring changes over time in habilitation professionals' perceptions and applications of the International Classification of Functioning, Disability and Health, version for Children and Youth (ICF-CY)

AIM

The aim was to investigate the implementation of the ICF-CY in Swedish habilitation services. Professionals' experiences of applying the classification in daily work were explored by posing three research questions: 1) How do habilitation professionals use the ICF-CY over time following in-service training of the ICF-CY?, 2) How do habilitation professionals perceive the utility of the ICF-CY over time?, and 3) How does the use of the ICF-CY correspond with the organizational service goals of child participation in their everyday life contexts?

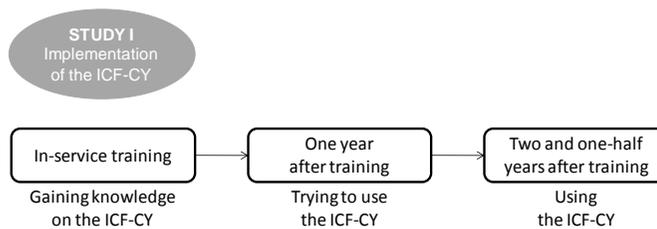


Figure 10.1. Time-points for data collection on utility of the ICF-CY in habilitation services

METHOD

The study employed a descriptive longitudinal design using a qualitative approach. Participants were provided in-service training on the ICF-CY by three researchers. Data were collected by means of a form, a questionnaire, and an open-ended question in varying combinations at three time points: During in-service training when professionals were introduced to the classification; one year after in-service training; and two and one-half years after in-service training (Figure 10.1). A combination of manifest and latent con-

tent analyses was used to summarize professionals' statements of the utility of the ICF-CY in daily work.

Professionals from 14 interdisciplinary habilitation teams in six Swedish county councils participated. During in-service training, all team members participated, i.e. 151 professionals aged 24 to 65 years, whereof 138 were women and 89% worked directly with children. Knowledge of the ICF-CY at the beginning of the training was none to limited. One year later, participants included the 113 professionals of the original group that were still employed. Two and a half years later, participants were 16 representatives selected by the directors because they had been especially involved in the implementation of the ICF-CY.

Qualitative data analyses of statements were performed with a combination of manifest and latent content analyses. Descriptive statistics were used supplemented with a paired samples t-test to analyze professionals' knowledge of the ICF-CY over time and Pearson's χ^2 to investigate the nature of the statements and changes over time.

RESULTS

The ICF-CY was primarily used for practical work such as habilitation planning, including problem-solving and decision-making, all important parts of the habilitation process. Application of the ICF-CY required development of new routines and adaptations of materials. 72% of participants reported that they used what they learned about the ICF-CY framework and they perceived that it expanded their perspectives, supporting analyses and communication of children's needs. The use of the ICF-CY appeared to enhance a focus on child participation, corresponding with the overall organizational goal for habilitation.

CONCLUSION

The ICF-CY seemed to provide a common framework for professionals in habilitation services for children and youth, enhancing their awareness of child participation and children's and families' views of child functioning in everyday life. Utility was perceived after a year but concrete applications required more time and adaptation of routines and materials. The findings indicated a need for proper tools to support professionals in focusing on

participation-related interventions. The development of code sets for assessment of participation in specific life situations was suggested by the participants to reduce the complexity of the ICF-CY and increase a more widespread usage of the ICF-CY.

STUDY II. Identifying Child Functioning from an ICF-CY Perspective. Everyday Life Situations Explored in Measures of Participation

AIM

The aim was to identify a limited set of everyday life situations of children and youth at different ages based on the assumption that frequently occurring ICF-CY categories in items across measures of participation might indicate common life situations of children. Three research questions were posed: 1) What measures of children's performance or participation are described in selected articles?, 2) What differences in content may be found when items in the measures presented as performance and participation are linked to ICF-CY codes?, and 3) Which everyday life situations for children and youth emerge from items in these measures?

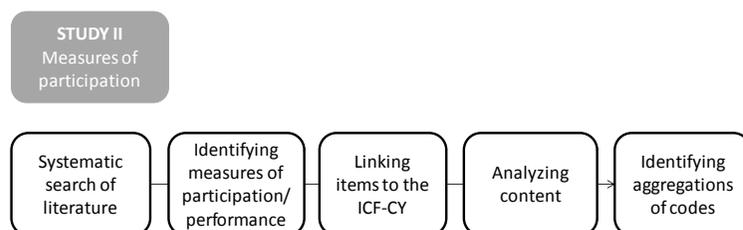


Figure 10.2. Stages preceding the identification of everyday life situations on the basis of measures of participation.

METHOD

The study was descriptive in nature and involved five stages (Figure 10.2): 1) systematic search of literature to find articles presenting measures for children and youth with disabilities, 2) identifying measures presented as

performance or participation in selected articles, 3) linking items in included measures to the ICF-CY, 4) analyzing content in measures of performance and participation, and 5) identifying aggregations of ICF-CY codes related to everyday life situations across measures presented as performance and participation. The systematic search focused on reviews from the year 2001 when the ICF was published. Included articles described measures used for individual children with or at risk for developmental delay or autism; mobility, behavioural, or multiple disabilities. Included measures were multidimensional and self- or parent-reports intended for screening or outcome evaluation of individual children's functioning in home or community settings. When identifying content in selected measures, manifest content analysis was used supplemented with descriptive statistics.

RESULTS

In total, 164 full text papers were reviewed and 417 measures identified. Most existing measures focused on body functions or on ability to execute tasks independent of the environmental context. Only twelve measures fulfilled the inclusion criteria, of which six were presented as performance and six as participation. All the nine ICF-CY chapters in the component Activities and Participation were represented in measures presented as performance, compared with primarily five chapters in measures presented as participation (d4-d6; d8-d9). Measures for infant and toddlers were solely presented as performance and measures for adolescents primarily as participation. Three life situations for children and youth at all ages emerged from the items within selected measures: Walking and moving around, Engagement in play, and Recreation and leisure. In measures suitable for the youngest children, some more life situations that seemed related to 'development' emerged: Communicating, Changing and maintaining body position, Dressing, and Eating and drinking.

CONCLUSION

Since only a small number of life situations for children and youth emerged from items in selected measures, other sources were needed to identify everyday life situations with the purpose of enhancing the discourse on how children and youth experience participation in contexts where they usually spend time.

STUDY III. Professionals' Views of Children's Everyday Life Situations and the Relation to Participation

AIM

The aim was to determine professionals' views/perspectives of everyday life situations of importance for children and youth. In addition, the aim was to explore how the construct of life situation seemed to correlate with the construct of participation across categories in the ICF-CY component Activities and Participation. Four research questions were addressed: 1) Which everyday life situations for children are proposed by professionals and how do they relate to the ICF-CY chapters and categories?, 2) How do professionals' views of everyday life situations vary with their background characteristics, such as professional experience, working field, ICF/ICF-CY knowledge, home country of participant, or age group considered?, 3) How do professionals relate the everyday life situations to the ICF-CY key construct of participation across ICF-CY chapters and categories?, and 4) Which important everyday life situations emerge when integrating results from two concurrent data collections?

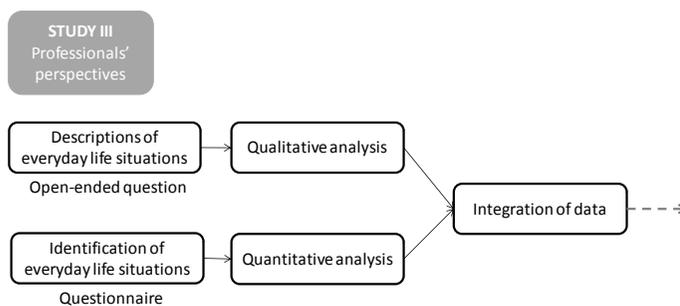


Figure 10.3. Integration of data from two concurrent data collections exploring professionals' perspectives of everyday life situations. Analyses continued in Study IV.

METHOD

The study had a concurrent mix methods design with an inductive approach (Figure 10.3). Supplementary qualitative and quantitative data were generated by means of one open-ended question on everyday life situations

important to assess and one questionnaire with items related to ICF-CY categories at 2nd level in the component Activities and Participation. The questionnaire was used to check if a category was perceived as participation and/or life situation.

Participants were multidisciplinary professionals and graduate students in child health and education in various countries (n=207 and 297 respectively). Responses to the open-ended question were linked to the ICF-CY. The distribution of 1264 linkages was compared with how participants checked life situations in the questionnaire. Statistics used were Pearson's r , Spearman's rho, and Pearson's χ^2 .

RESULTS

Professionals' views of everyday life situations related to background characteristics revealed some significant differences. Participants from organizations outside school or services for children with disabilities identified fewer everyday life situations, suggesting that teachers and therapists were more motivated to assess children's daily routines and other frequently occurring activities. Participants' home country seemed influential probably explained by policies and cultural-related daily routines. Also the age of children on which participants based their responses made difference. For the youngest children, developmental mile stones were determined as everyday life situations whereas these shifted towards societal involvement for adolescents. The correlation between participation and life situation became stronger the more complex and context specific the chapter, i.e. the correlation was strongest for the later ICF-CY chapters Relationships (d7), Major life areas (d8), and Community life (d9).

CONCLUSION

Eleven everyday life situations were explored as potential areas to be included in code sets and it was established that two age groups should be considered when developing code sets. However, the findings needed triangulation with other concurrent studies to provide corroborating evidence and add a family perspective.

STUDY IV. Identifying Children's Everyday Life Situations using an ICF-CY perspective

AIM

The aim was to determine a set of specific everyday life situations for children and youth aged 0-17 years by integrating data from several studies providing different perspectives. Four research questions were posed: 1) Which chapters at the 1st ICF-CY level may include everyday life situations for children and youth?, 2) Which categories at the 2nd ICF-CY level may include everyday life situations for children and youth?, 3) How do everyday life situations vary depending on children's ages?, and 4) How do the views of professionals and families (i.e. parents) agree?

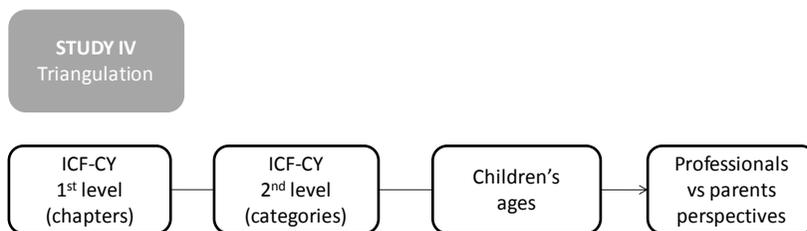


Figure 10.4. The four steps in the analyses of Study IV aiming to integrate data from six studies, capturing the perspectives of researchers, professionals, and parents.

METHOD

Triangulation of data was conducted by integrating the three data sets from Study II and III with three external data sets including the perspectives of parents and other significant persons' in children's networks. Data in all data sets had been linked to the ICF-CY and compared in four steps related to the 1st ICF-CY level (chapters), 2nd ICF-CY level (categories), children's ages, and perspective (professionals/parents) (Figure 10.4). In addition to descriptive statistics, Spearman's rho was used.

RESULTS

The analyses on the 1st ICF-CY level suggested that the chapters d3-d9 include everyday life situations. Supplementing analyses on the 2nd ICF-CY level identified six categories as everyday life situations for children in the combined age group 0-17 yrs. The categories were included in the chapters d3, d5, d6, d8, d9; no category was included in Mobility (d4) or Relationships (d7). Considering age groups, nine categories seemed suitable for younger children and seven for older children. In addition, sleep should probably be included for both age groups but is not part of the ICF-CY component Activities and Participation. Professionals described children's everyday life situations quite similar regardless of age but parents' views differed due to children's age. The views of professionals and parents seemed comparable for older children.

CONCLUSION

The triangulation identified everyday life situations to be considered in intervention planning for children and youth with disabilities and verified the appropriateness of different sets of everyday life situations for two age groups infants/preschoolers and school aged children/adolescents. This may serve as implications for future development of a new screening tool containing code sets from early childhood through adolescence.

II MAIN RESULTS

The results in Study I indicated that the ICF-CY could provide a common framework for professionals in habilitation services for children and youth. Participants perceived that using the framework expanded their perspectives, supported analyses and communication of children's needs, and enhanced their awareness of child participation and sensitivity about children's and families' views of everyday life situations. The ICF-CY was primarily considered during assessment and habilitation planning and its utility was perceived after a year. However, concrete implementation of the ICF-CY in daily work required more time and, above all, adaptation of materials and routines. In addition, the ICF-CY was considered too comprehensive and detailed for daily use and professionals suggested limited screening check lists for children's common life situations, such as mealtimes and sleep. Generally, the findings indicated utility but a need for proper tools to fit the comprehensive scope of the ICF-CY on functioning and disability and to reduce the complexity of the classification.

The results in studies II-IV established that everyday life situations differ between younger (0-6 yrs) and older children (7-17 yrs) with acts and tasks seeming most important for the younger age group and societal involvement for the older. These findings suggested that everyday life situations differ in context specificity depending on maturity and growing autonomy. Study IV showed that professionals' and parents' perceptions of everyday life situations differed for the younger children but that they seemed to agree for the older children. For each of the two age groups, linkages to the ICF-CY component Activities and Participation identified 8-10 categories at 2nd ICF-CY level as everyday life situations suitable as a basis for future development of brief code sets for child participation aiming to guide individualized assessment and intervention planning (Table 11.1). The identified categories highlighted that everyday life situations seem related to the late chapters d3-d9 and that Self-care (d5) and Major life areas (d8) were predominant.

To obtain a complete picture of everyday life situations, children and youth representing the two age groups should be involved in the future process of developing the screening tool.

Table 11.1 ICF-CY categories identified in this dissertation as everyday life situations for younger and older children

ICF-CY category		Younger 0-6 yrs	Older 7-17 yrs
d3 Communication			
d399	Communication	X	
d4 Mobility			
d450-d469	Walking and moving around	X	X
d5 Self-care			
d510-d530	Hygiene	X	X
d540	Dressing	X	
d550-d560	Eating and drinking	X	X
(d569)	Sleeping	X	X
d6 Domestic life			
d630-d649	Household tasks	X	X
d7 Interpersonal interactions and relationships			
d760	Family relationships	X	
d8 Major life areas			
d820	School education		X
d880	Engagement in play	X	X
d9 Community, social, and civic life			
d920	Recreation and leisure *	X	X
			(Social, Recreation, Leisure)

* This category is divided into three everyday life situations for older children (7-17 yrs), see section 12.2.

12 DISCUSSION

The aims of the dissertation were a) to investigate how habilitation professionals perceive the utility of the ICF-CY in clinical work and b) to identify everyday life situations specific for children and youth aged 0-17 years. This section will discuss experiences built up when applying the ICF-CY, and the implications for the main results.

12.1 IMPLEMENTATION OF THE ICF-CY

In this dissertation, research was conducted *on* as well as *with* the ICF-CY and the use of the classification runs like a thread through all the work. This section purposes to add some reflections about the implementation process.

In Study I, in-service training on the ICF-CY was conducted to support the implementation in habilitation work. During the training sessions, the ICF-CY model was presented as a means to use the 360° fish-eye perspective suggested by Leonardi and Martinuzzi (2009), intending to broaden professionals' focus of intervention to include all aspects of the children's lives (McLeod & Bleile, 2004; Thomas-Stonell, et al., 2009). The training was also aimed to change professionals' perspectives 180° intending to make them regard needs and discuss solutions from the children's points of views before their own professional views. The altered perspectives seemed to have intended effect on participants' thoughts, but not on sustainable team adoption. One year after the training, more than a quarter of participants were reported as 'non-users'. Because the in-service training was not tailored to different groups of professionals, these participants most likely knew nothing about the ICF-CY before training and therefore would have needed a different agenda to become competent enough to use it in daily work (Pless, et al., 2009). One further thing to be noted is that professionals' positive attitudes towards the classification decreased over time while neutral statements increased. A plausible explanation relates to the distribution of statements among categories, with a significant high proportion reflecting a need for applications at an organizational level at the last time-point. It seemed that the more professionals penetrated into the classifica-

tion, the more they realized the complexity but also that they started think of solutions.

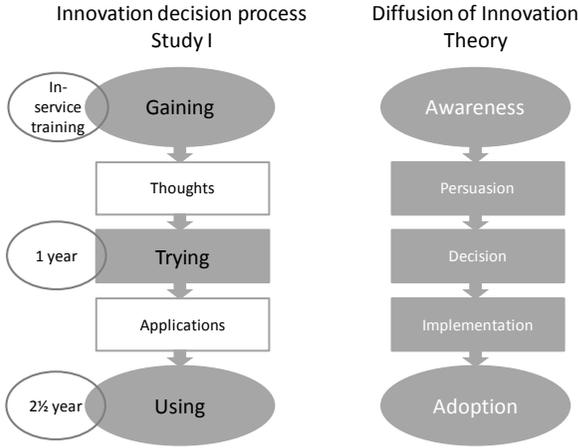


Figure 12.1. Implementation of the ICF-CY in habilitation work (Study I) compared with the steps described in the diffusion of innovation theory by Rogers (2003).

The longitudinal design of Study I made it possible to monitor implementation of the ICF-CY over time, from professionals gaining knowledge on the classification, through trying the framework to using it (Figure 12.1) (Cheetham & Chivers, 2001; Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004; Rogers, 2003). The construct of *implementation* is by Greenhalgh (2004) described as the process of realization of the use of a new idea. Despite the heterogeneous groups of participants at the three time-points, individual team members experienced relative advantages during the first year and the framework seemed compatible with habilitation values. However, for the teams as a whole, as reported by representatives at the last time point, implementation of the ICF-CY required time and was understood as a complex innovation not necessarily improving team collaboration. This might be due to a lack of previously adapted materials and routines but also because of different levels of knowledge and different motivation for using it. For example, after a year, all speech therapists and most of occupational therapists used it but less than half of the psychologists. During the training, some psychologist commented that the content

did not fit their discipline and that they already had all assessment materials they needed. This points to the importance of adapting training to individual participants, so that they perceive relative advantage of the innovation, enhancing their motivation to examine how it could be compatible with traditional ways of working (Greenhalgh, et al., 2004). Experiences of Study I also point to the importance of well-planned implementation processes with preparation of materials and predefined usage areas.

The study could not tell if the implementation had a direct impact of the work with families. However, preliminary findings in a concurrent study by Klang and Almqvist (in prep) suggest that the knowledge on the ICF-CY did not affect the content in habilitation plans in the short term. Despite the doubts discussed in this section, Study I and related research suggest that instructor-led learning formats are effective training mechanisms and that a sustained use of the ICF-CY may provide stronger teams (Martinuzzi, et al., 2010; Pless, et al., 2009; Reed et al., 2008; Rentsch, et al., 2003; Roelofsen, The, Beckerman, Lankhorst, & Bouter, 2002; Tempest & McIntyre, 2006). It may mean clarified team roles, improved competence in interdisciplinary reasoning, and a more systematic approach to habilitation tasks. However, the latter statements are not confirmed in the present research. Most likely, assessment tools are needed to fit the comprehensive scope of the ICF-CY on functioning and disability and contribute to a team common use in daily work.

12.2 EVERYDAY LIFE SITUATIONS OF CHILDREN

Children's *life situations* are the core of this dissertation. With the addition *everyday*, the life situations capture what happens regularly, i.e. episodes that occur frequently in the natural environments where children usually spend time. As general life situations of children and expectations on child functioning vary across developmental stages, different 'sets of everyday life situations' were anticipated for at least three age groups: preschoolers, school aged children, and adolescents, most likely with an additional set for infants and toddlers. Those age ranges had been in line with the recently identified developmental code sets for children (Ellingsen, 2011). However, for life situations wider age spans seemed appropriate, merging the preschool ages and the school ages. Differences between younger and older

children emerged early and Study III distinguished preschoolers and adolescence but could not place the school-aged children. Finally, two age groups emerged, suggesting that for preschoolers, everyday life situations are to a high extent related to developmental milestones, most likely because these situations include learning opportunities and the tasks are performed with considerable volition and engagement until they become automated (see Table 11.1) (Adolph, 2008; Dunst, Bruder, et al., 2006; McConachie, et al., 2006). For school-aged children and adolescents (7-17 yrs), the situations increased in complexity and social involvement (Badley, 2008; Granlund, et al., Accepted). The wider age spans seem natural since the planned screening tool with code sets should not be referred to as norm based but rather developmental based. As children in general and children with disabilities in particular differ in development, a limitation to two 'sets of code sets' can provide a greater scope for individual planning of interventions.

Everyday life situations that will be the basis for participation focused brief code sets ingoing in a future screening tool were identified in the present dissertation. However, appropriate ICF-CY categories ingoing as content in the planned code sets and intending to explain participation, were not identified. Everyday life situations are assumed to include different aspects dependent on developmental age. For example Walking and moving around most likely focus on the ability to walk for the younger children and on the part moving around for the older, suggesting this as a more complex activity, probably including the motivation, decision making, planning, and realization of moving from one place to the other. Hygiene may focus on the ability to wash body parts or brush the teeth for the youngest but include grooming related to specific situational requirements for the older. At last, Eating and drinking will most likely be named Mealtime as an everyday life situation. It is not about eating disorders but about the functional eating including routines surrounding a meal. One can imagine that for the youngest children this include handling forks and knives and behaving properly whereas for adolescence the code set Mealtime might include categories that concern managing diet (d5701) and body functions such as anemia and growth maintenance functions. This indicates the need for age-related adaptation of the content in code sets in a future tool but also for adaptation of the titles.

No everyday life situation was related to the ICF-CY chapters Learning and applying knowledge (d1) and General tasks and demands (d2), most likely because these chapters include basic skills that are important across areas of functioning and constitute prerequisites for involvement in most life situations (Lee, 2011; WHO, 2007). It was expected, though, that Communication (d3) and Relationships (d7) should be included for both age groups. Communication got high ranks when professionals responded the questionnaire in Study III and conversations were closely related to participation. Nevertheless, when integrating proposals from professionals and parents based on open-ended questions, communication qualified as an everyday life situation in the younger age group only, which is consistent with another study conducted in the same period (Ståhl, Enskär, Almborg, & Granlund, 2011). However, considering how much adolescents use new technology, communication seems to be a big part of their everyday activities. Explanations to the absence might be twofold. First, the list of everyday life situations is prepared from an adult perspective and second, communication is most likely part of what happens during spare time and thereby included in the social aspect of recreation and leisure. As displayed in Table 11.1, neither Dressing qualified in the older age group. Because this is part of for example morning rituals and with the assumption that the task is automated, dressing is not an everyday life situation in itself, but all those rituals in total could have qualified as one.

Relationships (d7) got high ranks in three of the six data sets in Study IV. All six categories belonging to this chapter seemed closely related to participation. However, only one category, Family relationships, became included in the list of everyday life situations for the youngest children and no category for the older. A plausible explanation is that also this chapter includes prerequisites for involvement. Although this chapter is suggested to be structured as participation (Whiteneck & Dijkers, 2009; WHO, 2007), the ICF-CY description of the chapter and definitions of categories may bring to mind more basic skills describing behavior rather than situations. However, the author of this dissertation experienced that young people might express interactions in a way that provide another linking of information. Getting the opportunity to discuss participation with a group of six adolescents 13-16 years (2 boys and 4 girls) with a variety of disabilities during a summer camp 2009, they emphasized that social roles differ for them from time to time, primarily depending on the expectations from people around.

Relationships with friends were important, including how to begin and maintain relationships, what friendship requires of both themselves and others, and how good friends act. These aspects belong indeed to the activities and participation chapter Relationships (d7) in addition to the component Environmental factors with categories covering support and attitudes. As discussed in Study III, relationship might not be an everyday life situation in itself but constitute an important prerequisite for participation. Therefore, categories related to interaction will probably be included in code sets to explain success or failure.

Informal leisure activities were another area of importance for the adolescents. They mentioned relaxing activities, e.g. watching TV but also social activities, e.g. going to the movies or being on vacation. As explored in previous research, informal activities might cause anxiety for school aged children with disabilities, whereas formal activities seemed to imply participation in the same conditions as others (Eriksson, 2006; Eriksson & Granlund, 2004b, In prep; Stenhammar, 2010). Regarding these findings, it seemed appropriate to specify everyday life situations connected to recreation and leisure for the older children. The future code sets will therefore capture three types of activities related to chapter d9: 1) *social*, i.e. activities in which children are engaging informally with peers, for example going to the movies or hanging out with friends; 2) *recreational*, i.e. activities that are formally organized, for example structured sports and music lessons; and 3) *leisure*, i.e. more passive and informal activities, for example reading a book or watching TV (Imms, Reilly, Carlin, & Dodd, 2008; Law, et al., 2006; Solish, et al., 2009). For the youngest children, one code set focusing on social activities might be sufficient since the other types of recreational activities are most likely part of family relationships. The adolescents at the summer camp also mentioned *sleep*, justifying the inclusion of sleeping in the final list of everyday life situations, despite the absence in data collected from parents. In the light of these remarks, the final list of categories appropriate as code sets includes ten everyday life situations for younger children (0-6 yrs) and ten for older (7-17 yrs) (Table 11.1).

Household tasks can be found in the final list. Study IV, however, showed that professionals pointed out these tasks as important to a significant lower extent as parents did. Professionals' moderate attention to these tasks is also recognizable in other recently conducted Swedish studies (M.

Adolfsson & Granlund, 2008; Klang & Almqvist, In prep; Ståhl, et al., 2011) although such tasks occur daily and represent potential areas for learning opportunities. As an example, setting the table includes elements such as planning, decision-making, calculating, acquiring information, carrying, experiencing light or heavy weights, walking, and relating with parents, siblings, or friends. Using this frequently occurring family routine as a learning opportunity, parents support the child's development of body functions, a wide range of functional skills, and also self-determination skills (Wehmeyer & Schalock, 2001). In addition, professionals can contribute to decreased parental stress and increased well-being if calling attention to this easily provided 'intervention' in the natural environment (Duis, et al., 1997; Fulkerson, et al., 2006; Keysor, et al., 2006). At the same time, this 'intervention' would promote a child's participation in domestic life. According to Dunst and his colleagues (2006), strategies that make use of everyday life situations to provide children possibilities to develop a variation of acts and tasks are preferable compared with implementation of interventions in home activities structured by professionals, which is what usually occurs. The difference between the strategies is subtle. However, as findings point to a low professional consideration to children's domestic life, they indicate that those possibilities are not fully taken into account.

12.3 PLANNING OF INTERVENTIONS

Although Study I indicated that the ICF-CY could be a common framework for interdisciplinary teams providing wider perspectives on children's participation in everyday life situations, such a holistic approach was not yet integrated in habilitation processes. For professionals, it requires collaboration with focus on how children deal with everyday life situations and assessment combining information about the children, available resources, and context in order to set common participation goals that can be attained via a variety of discipline-specific interventions. Interventions based on goals that are set together with children and their parents are evidently most efficient but it is uncertain to what extent professionals include children's own preferences and consider their rights to choose activities (Ketelaar et al., 2010; Michelsen, 2010; Stenhammar, 2010). It might be as Morris (2003) points out, that young disabled people often have little control over their

lives and that other people make decisions for them, not necessarily based on a broad perspective on how they deal with everyday life situations.

Study II indicated that interdisciplinary tools for this purpose were rare, though, it was depicted several years ago as a key issue for development of Swedish habilitation services in the future (Björck-Åkesson & Granlund, 2005; Simeonsson, et al., 2010). Most common were discipline specific measures used by psychologists and therapists in medical disciplines, constructed as tests or observations. They were not self- or proxy-reported, which has proven to be preferable in terms of participation (Coster & Khetani, 2007; Whiteneck, 2006). Even measures that are presented as participation measures might lack consideration to a child's preferences, for example the LIFE-H (Assessment of Life Habits for children) that was included in Study II (Morris, 2009). Although new methods and measures with figures and symbols have been developed during the last 10 years to support self-reports (Allbrink Oscarson & Eliasson, 2006; Bornman & Murphy, 2006; King, et al., 2004; King, et al., 2007; Lidström, 2005; Missiuna, Pollock, Law, Walter, & Cavey, 2006; Sturgess, 2007; Ullenhag, 2010; Vroland-Nordstrand & Krumlinde-Sundholm, Submitted-a, Submitted-b), Stenhammar (2010) found that children's participation in habilitation processes is still limited except for adolescents from the age of 14. She questions whether participation in this context means – in addition to being involved - to make decisions without support of others, which may be understood by professionals as far too much responsibility for a child. It may indicate that the shift from an expert service model to a consultative model is not yet reflected in practices and, based on the results of this dissertation; the absence of collaborative interdisciplinary measures focusing on participation is a barrier.

Another plausible barrier for professionals to focus on how children deal with everyday life situations is that Swedish habilitation teams by tradition include a preponderance of medical disciplines (see Figure 6.1). It might mean an imbalance between interventions with a predominant focus on body functions and activity, raising expectations on the possibility to 'fix the child' (Björck-Åkesson & Granlund, 2005; Nordenfelt, 2006; Simeonsson, et al., 2010). Study III explored a slight cultural difference in ratings of areas important to assess, suggesting that professionals in Sweden were not as motivated to assess acts and developmental milestones as they

were in USA and Portugal. It may mean that Swedes to a larger extent focus on children's societal involvement in natural environments.

Working against preservation of traditional clinical practices and towards a habilitation with a common focus on societal involvement, requires attention to children's different social roles (Badley, 2008; Baird & Vargus-Adams, 2010; Davis, Wong, Badley, & Gignac, 2009). It is not only whether children perform a specific role but also whether they are able to engage in everyday life situations in the way and at the time they want. Focusing on social roles, such as being a peer or playing with other children, might motivate interventions and highlight children's strengths, not only shortcomings. For example, during shared cooperative activities purposing to build a Lego house or playing Nintendo, acts such as maintain sitting and manipulating are included but also tasks such as planning, problem solving, and interaction (Sturgess, 2009a, 2009b). If a child has problems in one of these areas or several, interventions that are directly related to the social role of being a playmate might enhance children's and their parents' motivation for energy and time-consuming interventions rather than interventions solely related to the activity 'sitting'.

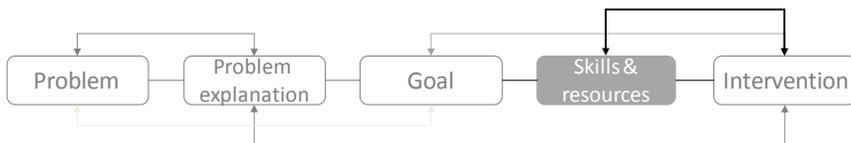


Figure 12.2. The problem solving model with an asset-based approach.

By focusing on participation, a needs-based approach to intervention with a strong focus on problems, deficiencies and needs can be reoriented to an asset-based approach focusing on skills and resources (Bornman & Rose, 2010; Ebersöhn & Eloff, 2006; Eloff & Ebersöhn, 2001). From that point of view, inability to perform acts or tasks do not necessarily imply that children will have participation restrictions. They can take part, engage, and experience play success in the activities without positioning a single Lego piece because with self-determination skills they can control the situation and experience well-being and a good sense of coherence (Antonovsky,

2005; Wehmeyer, 2007). Using an asset-based approach in problem solving may integrate an additional step in the process aiming to highlight skills and resources when deciding on interventions appropriate to specific goals (Figure 12.2).

Participation has been identified as a strong predictor of well-being and life satisfaction. Other predictors are functional status and self-perceptions whereas body functions and structures do not seem as important (Becker, 2006; Meisels & Shonkoff, 2000; Pierce & Hanks, 2006; WHO, 2007). This provides arguments to further implementation of the ICF-CY in clinical practices. The multidimensional framework might contribute to an interdisciplinary way of work and support professionals and parents in taking multiple perspectives on functioning and disability into account when deciding on interventions.

12.4 IMPLICATIONS

12.4.1 IMPLICATIONS FOR CLINICAL WORK

Implementation of the ICF-CY in clinical work followed the many stages that are described by the diffusion of innovation theory (Rogers, 2003) (see Figure 12.1). A qualitative improvement and increased efficiency of interdisciplinary work would justify the time and effort an implementation of the ICF-CY implies. Because habilitation services at present time are struggling with limited resources, it is of special importance to develop effective interdisciplinary team approaches. Efficiency might include improved target definitions and a common ability to conduct assessments focusing on participation. Efficiency also requires a common ability to connect desired changes with interventions, not only to justify the intervention, but also to better orient resources and efforts. Another aspect of efficiency might be that considerations to the interactive ICF-CY model provide a less needs-based approach implying that not all children with impairments or activity limitations are automatically dependent on habilitation services.

The large number of identified measures in Study II generated reflections. The extremely small proportion of participation measures suggests that services for children with disabilities have not yet integrated methods to connect discipline-specific findings to a holistic view of children's needs. The

variety of measures points to an overlap of measures and difficulty of knowing the possibilities offered by them. A systematic ICF-CY based comparison could give information about the breadth and the depth but also guide the selection of measures (Cieza, et al., 2005; Cieza & Stucki, 2005; Geyh, Kurt, et al., 2004). Also in Swedish habilitation services many measures are available and in use. In conjunction with the in-service training in Study I, the 151 participants identified 137 assessment measures that they had used during the last 6 months. This fact raised questions about how familiar professionals really are with all these tools but also if children are subjected to unnecessary assessment because of overlapping measures. Preferable, a limited kit of the most relevant measures for habilitation services could be identified on a national level. This would enable a more consistent assessment and follow-up of functional status of children with the most frequent problems. It would probably also increase professionals' knowledge about the measures and facilitate interdisciplinary discussions about results of assessment.

The bio-psycho-social framework of ICF-CY reflects a systems theory perspective (Wachs, 2000), which is consistent with an interdisciplinary approach for clinical practices. The interactive ICF-CY model of functioning reflects the ongoing influence of factors at different levels in an interactive and hierarchical system (Bhaskar & Danermark, 2006; Danermark, 2005; Danermark, Ekström, Jakobsen, & Karlsson, 2002). To understand the complex phenomenon 'child participation in everyday life situations', all the dimensions of the model may be taken into account, which can be done if habilitation professionals integrate information from all four competence areas in addition to what the children and their families tell about participation. This way of working would be consistent with both the overarching goal of habilitation services and the Swedish national laws and policies.

In this research, information was sought in a variety of sources to obtain a general set of everyday life situations. To begin individualized planning, professionals need to consider each child's specific everyday life situations because of substantial 'within-situation' variations that depend on how factors impact participation in specific situations.

12.4.2 IMPLICATIONS FOR RESEARCH

The topic of the present dissertation was in line with a third generation research of early intervention, aiming to provide guidelines for intervention programs that target the benefit of clients. It means an extension of previous generations, which have focused on quality, effectiveness and legislations, and an extension of previous guidelines meant to be of value in daily work of clinicians and families (Guralnick, 1997, 2007; Wyngaarden Krauss, 1997). The studies in the current dissertation will prepare for the further development of a screening tool aiming to support children with disabilities to get their voices heard and influence participation in the everyday life situations that they themselves see as most important.

The ICF-CY framework supported analyses in three of the studies and the experiences it provided might be useful for other purposes. By linking information to ICF-CY codes, qualitative data were quantified and possible to integrate with quantitative data. However, the linkage procedure was not uncomplicated, as discussed in the section Methodological considerations (see 8.3.3). The ICF linking rules were not perceived sufficient when using the ICF-CY, though; one can look forward to the outcome of an ongoing revision performed by Cieza and her colleagues (Cieza, 2005; Cieza, personal contact, 16th of June 2008). In addition, another insufficiency was explored, i.e. the category 'sleep' that is only included as sleep functions in the component Body functions. In this dissertation, it is proposed that sleep activities should be an additional category in the activities and participation chapter Self-care.

Based on experiences in this dissertation, the most appropriate option to view the constructs of activity and participation in relation to everyday life situations seems option 2 listed in the ICF-CY (Annex 3), which is: "partial overlap between sets of activities and participation domains" (Table 12.1). This option might also be preferable in the view of children's varying levels of development. To distinguish how categories can be coded for the structure of option 2 in comparison with suggestions for option 3, the overlap would be further specified as "using early categories in chapters as activities and late categories as participation". This approach may guide the selection of categories for code sets, both to determine which everyday life situations to choose and to identify content for different age groups. Most likely, early

categories in over-lapping dimensions fit into code sets for the younger children whereas late categories are more appropriate for the older.

Table 12.1 *Structure for the constructs of activity and participation in relation to everyday life situations*

Chapter (domain)	Activity	Participation
d1	Learning and applying knowledge	
d2	General tasks and demands	
d3	Communication	Communication
d4	Mobility	Mobility
d5	Self-care	Self-care
d6	Domestic life	Domestic life
d7		Interpersonal interactions and relationships
d8		Major life areas
d9		Community, social and civic life

12.4.3 THE KEY CONSTRUCTS

Understanding the key constructs of the ICF-CY revealed some problems. The relation between *life situation* and *participation*, described as ‘participation is involvement in a life situation’, was not quite clear. Aiming to provide clarification, the expected relation between constructs were investigated in Study III, finding that the majority of respondents perceived several categories as life situations but with weak correlation to participation. Participants might have understood a life situation as a ‘routine’ rather than a ‘sequence of actions with meaning for the child’ and therefore checked everything that could possibly occur during a day. In addition, *activity* was sometimes understood synonymous with *life situation*, which caused confusion. In everyday language, activity may be used for special events, such as doing sports or going to the movies. In the ICF-CY, however, the construct includes individual capacity, i.e. what children can do, such as tossing a ball, walking, or solving a problem. This illustrates the importance to define clearly the constructs to make the ICF-CY work as a common language within and between organizations.

In the ICF-CY, children's involvement in life situations, i.e. participation, is given a prominent significance (WHO, 2007). However, the ICF-CY model does not display how the construct of life situation is connected to the other constructs included in the model. It does not capture the dynamics occurring in different natural environments with varying conditions for the execution of tasks as well as for participation. These dynamics might be clearer understood with a metaphor built on the alternative constructs introduced by Badley (2008), exchanging 'participation' with 'societal involvement'. If one imagines natural environments as scenes for children's actions, each specific life situation is a drama that is going on. Several interacting factors affect the acting. *Body functions* and *structures* constitute the actor, *acts* mean to meet the demands set by the drama, and *tasks* are determined by the manuscript and the choreography. On stage, the scenery includes *environmental factors as scene setters* that may be barriers or facilitators for *involvement* in the drama. This metaphor shows how environmental factors affect participation by giving them a scene-setting role. To give an example, the social activity 'hanging out with friends' (drama/everyday life situation) takes place in a pub (scene/natural environment). Furnishings and equipment of the pub are environmental factors that provide scene setters. However, the interaction between the individual and the environment influences the pub visit, for example the choice to go to the pub, relationships with peers, decision-making to know what to eat and drink, ability to move around and sit on the chairs available, communication skills, and imagination. This emphasizes how the dynamics that occur in different everyday life situations are produced by a wide range of forces, making the participation change from time to time. It also confirms the assumption that everyday life situations could be connected to one ICF-CY category but that the participation may be explained by several categories, in some cases representing all dimensions of the model.

The wide range of forces that have an impact on children's feeling of well-being may be expressed in other terms. According to Nordenfelt (2006), arguing for an additional 'opportunity' qualifier, the combination of three constructs provides a child's practical possibility for action in everyday life situations. First, *ability* is the children's inner possibilities for action, which is closely related to volition. Correlated to the ICF-CY, ability is about activity whereas volition is about body functions and personal factors, maybe more explicitly described as characters affecting decision-making (Morris,

2009). Second, *opportunity* includes physical and social accessibility, which is dependent on kind of tasks. Finally, *possibility* sets the scene for participation, i.e. the frame within which participation is defined. Ability and volition are conditions inherent in the child whereas opportunity is an external condition (Michelsen, 2010; Molin, 2004; Nordenfelt, 2006; Shonkoff & Phillips, 2000). *Capability* is another analogue term that by Morris (2009) was suggested as an additional approach to evaluate participation. However, as capability is easily confused with the construct of capacity and sometimes defined similarly (Östensjö, et al., 2006), the use of the three constructs suggested by Nordenfelt seems preferable to provide a better understanding of the dynamics explaining why children's participation differs from time to time. Also Granlund et al. (accepted) discuss how the context creates conditions for children's involvement and argue for a third 'participation' qualifier, proposing that as the only way to describe how individual children experience the impact of various contexts. This information is essential to add to ratings from others because only assuring opportunities for participation, i.e. issues of availability and accessibility to the same life situations as everyone else, does not provide information about children's feeling of belonging and engagement.

In Study III, professionals related everyday life situations not only to a 'drama' that is going on, but to a range of interacting factors. They pointed out body functions, e.g. appetite, pain, and weight maintenance; acts, e.g. sitting, reading, and managing behavior; tasks, e.g. eating, putting on clothes, and household tasks; participation such as entering a new group of people, interplay with peers, and school education; and environmental factors, e.g. siblings and support systems. Those responses reflected primarily narrow perspectives, most likely based on discipline-specific experiences with limited regard to children's everyday life situations as a whole and very much consistent with the many measures identified but excluded in Study II. A wider perspective, based on interdisciplinary experiences and with focus on children's participation, would benefit an individualized planning of interventions.

12.5 LIMITATIONS

In this dissertation, the main limitations concern samples. Study I comprised discrepancies in the number of respondents and response rates at the three time points, affecting the longitudinal approach of the study in the sense that it followed the use of ICF-CY over time rather than participants. During the first two data collections, which had been agreed on with directors for the habilitation services, all members of participating teams were asked to provide data. However, the first time only 2/3 of participants handed in the PMI-Form, which could possibly have given an imbalance in the responses, and at the third collection, a limited group of representatives provided information because it was not decided in forehand. This fact might have decreased the comparability of data. Despite this, the data were perceived as credible and the participants were judged representative because they were selected by the directors as especially involved in the implementation process. Although participants might have held back their individual perspectives, habilitation professionals are accustomed to perform a team role and in this case, they provided data reflecting the impact of the ICF-CY in daily work for the team as a whole. Another plausible argument for low comparability was various data collection methods used at the three time-points, also explained by continuous planning of the investigation. However, since all questions were open-ended, responses were possible to handle equal in the content analyses.

In Study II, the search for measures of participation missed some relevant measures. It is likely because the search was limited to journal articles within a limited time space and to measures used in home or community settings due to the responsibilities that apply to Swedish habilitation services (Björck-Åkesson & Granlund, 2005; Granat, et al., 2002). More measures might have provided a broader view of life situations. In Study III, participants represented a wide range of disciplines, academic levels, and cultures making the size of each group different. However, the samples envisaged a common focus since participants belonged to two main organizations; child health care and education and the wide range contributed to a desired variation of child-related experiences. Finally, Study IV included data from various sources, some of them including small samples. Despite the disadvantage of limited samples, the various sources represented an advantage because it enabled syntheses of different perspectives.

A limitation for credible comparisons of data might be the different perspectives of professionals and parents emerging in Study IV. Professionals' answers were most likely associated with assessment methods focusing on daily routines whereas parents' answers might have been associated with discretionary episodes that occur during daytime without special focus on regular routines. This points to the importance of clear and specific instructions, though not possible when included data are collected from external studies as in the present dissertation.

Conducting research both on and with the ICF-CY might provide another limitation. However, the ICF-CY was perceived useful by professionals in Study I, and it became natural to investigate further, how the classification could be used for the purposes of the dissertation. Moreover, a potential usefulness was known from other Swedish studies (Ibragimova, et al., 2009; Pless, et al., 2009). The limiting factor was restricting the theoretical basis for the research to one conceptual framework. It might have resulted in a narrow perspective, although the classification reflects a systems theory perspective, taking into account how children grow and develop and how child participation in everyday life situations is influenced by the environment (Bronfenbrenner & Ceci, 1994; Wachs, 2000; WHO, 2007). Besides, using the ICF-CY contributed to an understanding of the limitations of the classification and increased clarity of constructs.

A future challenge will be to include the perspective of children and to develop the screening tool by identifying content for each code set. Results in the present dissertation has prepared for the tool by identifying a set of everyday life situations as a basis for brief code sets for child participation.

13 CONCLUSION

As the ICF-CY framework was both field trialled and used for analyses in the dissertation, it runs as a thread through the research, depicting both advantages and disadvantages of using the conceptual framework. Because the relation between the constructs of participation and life situations of the ICF-CY model is not clear, participation was assumed directly affected by the tasks required, the environmental factors, and the natural environment in which a child spend time at the moment. Life situations were assumed to be represented by the life areas included in the component Activities and Participation. Based on professionals' ratings, the relation between participation and life situation was established as stronger the more complex and context specific the chapter. According to the distribution of activity and participation across the component chapters, the results suggested a partial overlap between the chapters with early categories appropriate for younger children whereas late categories seemed more appropriate for the older.

To assign information to the ICF-CY, the ICF linking rules by Cieza et al., were not sufficient. A set of specific ICF-CY linking rules were set up (see 8.3.3) and should serve as a support for other researchers when using the classification for comparison of content in measures or verbal statements.

According to the initial study, when the utility of the ICF-CY for clinical work was investigated, professionals perceived that it provided a common framework in habilitation services. Findings indicated enhanced awareness of child participation and children's and families' views of functioning in everyday life, a focus corresponding with the organizational goal for habilitation services. Applications in daily work concerned primarily assessment and habilitation planning. Barriers for introduction of the framework in clinical work were in firsthand the comprehensiveness of the classification and the time it took to learn and apply the ICF-CY. Reduced sets of categories were decided for assessment of participation in specific everyday life situations.

The other three studies, when everyday life situations specific for children were investigated, established the appropriateness of two sets of ten everyday life situations as a basis for code sets adapted for younger and older

children respectively (see Table 11.1). Differences concerned context specificity depending on maturity and growing autonomy and minor cultural discrepancies were noted. For infants/preschoolers (0-6 yrs), everyday life situations focused on developmental milestones whereas social involvement was prominent for school aged children/adolescents (7-17 yrs).

The sample of everyday life situations, based on professionals' and parents' statements, included most chapters in the ICF-CY component Activities and Participation. However the two earliest, Learning and applying knowledge (d1) and General tasks and demands (d2), were excluded since they capture basic skills that are important across areas of functioning and constitute prerequisites for participation. Professionals described everyday life situations regardless of age, most likely based on traditional assessment measures, whereas parents' descriptions differed due to children's age. The most obvious differences concerned Communication (d3) and Mobility (d4); parents suggested these chapters important as everyday life only for the younger children. Professionals and parents agreed on two chapters that most likely included everyday life situations: Self-care (d5) and Major life areas (d8). However, they did not agree on Domestic life (d6) and Social life (d9); professionals ranked these two chapters significant lower.

As the samples of everyday life situations reflect the perspectives of adults, further research has to add the perspective of children and youth. Findings also pointed out the importance to adapt code sets for the different cultures where they will be used. It will be critical to name the everyday life situations because the titles of the ICF-CY categories might not bring into mind "routines that are frequently occurring, comprise sequences of actions, can be accomplished using a variety of tasks, and are goal-directed with meaning for the children" in accordance with the definition of life situation in this research. The two sets of everyday life situations will be the basis for the development of code sets included in the planned screening tool intended for self- or proxy-report from early childhood through adolescence. To identify content in the code sets and adapt it to the two age groups, Delphi processes will be used in future studies together with professionals, parents, and children.

14 RECOMMENDATIONS

IMPLEMENTING THE ICF-CY IN CLINICAL PRACTICES

To support implementation, the recommendation is that decisions for what purpose the ICF-CY should be used in everyday work are taken in beforehand and that adaptations of systems and routines are prepared.

To plan the implementation and guide colleagues through the process, the recommendation is to engage a task force that includes experienced professionals and is headed by a person familiar with the ICF-CY and its practical use.

To provide effective training, the recommendation is to engage instructors, allocate time over a long period, and relate the training to everyday working context of participants.

To encourage the learning process of individual participants, the recommendation is that the training is tailored to different groups of professionals based on their previous knowledge.

To improve the conditions for use of the ICF-CY in interdisciplinary teams, the recommendation is that the training is organized into two parts: one common for all disciplines and one discipline specific.

APPLYING THE ICF-CY IN CLINICAL WORK

To compile information on children's functioning and disability, the recommendation is to supplement information about disease and diagnosis with functional descriptions based on the ICF-CY model.

To avoid that children are subjected to unnecessary assessment, the recommendation is to determine a limited kit of the most relevant measures to be used in assessment and follow-up of functional status of children.

To provide a holistic picture of children's everyday life situations, the recommendation is that professionals in interdisciplinary teams use the ICF-CY as a common framework to profile children's functioning.

To prove the use of a holistic picture of children's everyday life situations, the recommendation is that professionals increase focus on the ICF-CY chapters Domestic life (d6), including household tasks, and Social life (d9), including recreation and leisure.

To motivate interventions, the recommendation is that professionals in interdisciplinary teams set common participation goals together with children and parents reflecting children's preferences and thereafter continuously relate discipline-specific interventions to these goals.

To achieve sustainable interventions, the recommendation is that professionals teach parents how to integrate learning opportunities in everyday life situations as opposed to integrate training in home settings.

ICF-CY REVISIONS

In the on-going revision of the ICF linking rules, including adaptations to the ICF-CY, the recommendation is to clarify

- that use of manifest analysis is preferable
- how the concepts play and games should be separated
- how to link activities occurring in preschool/school
- how to separate learning from school education
- how to relate 'behavior' to Body functions and to Activities and Participation
- how to link the sleeping activity.

In the on-going revision of the ICF-CY, the recommendation is to consider the

- need of a revised ICF-CY model
- need of clarification of constructs
- lack of sleeping as an activity within the component Activities and Participation with the suggestion to include it as a new code within Self-care (d569) and to include 'rest' close to 'relaxation' in the description of Recreation and Leisure (d920)
- difficulties to separate the concepts of play and games with the suggestion to exchange 'play' with 'games' in the title of d9200.

SUMMARY IN SWEDISH SVENSK SAMMANFATTNING

Denna sammanläggningsavhandling, som består av fyra delstudier, fokuserar på vardagliga livssituationer, det vill säga vardagssituationer, för barn och ungdomar. Grunden är att barn utvecklas genom att delta i aktiviteter som försiggår i de vanliga miljöer där barnen tillbringar sin vardag. Barn med funktionsnedsättning ska ges möjlighet att uttrycka sina önskningar och behov så att habiliteringspersonal vet vilka insatser som inledningsvis är mest viktiga och motiverande för barnen själva. WHO:s Internationella Klassifikation av funktionsstillstånd, funktionshinder och hälsa, versionen för barn och ungdom, ICF-CY, definierar olika aspekter av barns och ungas hälsa och livssituation och utgör konceptuellt ramverk för arbetet. Vid tidigare prövningar har ICF-CY bedömts intressant för klinisk användning och visat att kartläggningar görs noggrannare och med ett signifikant ökat fokus på delaktighet och omgivningsfaktorer. Den har dock bedömts som alltför omfattande. För att öka användbarheten av klassifikationen i dagligt arbete, kan code sets med för olika ändamål. ”utvalda bråkdelar” av ICF-CY kategorier användas. Fokus för detta avhandlingsarbete är att identifiera barns vanligaste vardagssituationer för att i ett senare arbete utveckla code sets med fokus på delaktighet i vardagssituationer.

Det långsiktiga målet för forskningen är ett tvärvetenskapligt ICF-CY baserat instrument för kartläggning av barn och ungdomar med funktionsnedsättningar. Det ska bestå av code sets och användas vid screening av barns och ungas fungerande i vardagen för att barnen ska kunna uttrycka hur de själva ser på sin situation och vad de i första hand önskar hjälp med från habiliteringen. De mera kortsiktiga mål, som rymts inom avhandlingen, har varit att i Studie I undersöka hur habiliteringspersonal uppfattar ICF-CY vid klinisk användning för att utifrån deras erfarenheter planera utvecklingen av instrumentet. Syftet för de efterföljande studierna har varit att identifiera en uppsättning av vardagssituationer som ska ligga tillgrund för utveckling av ICF-CY code sets. Dessutom har relationen mellan aktivitet, delaktighet och livssituation studerats, eftersom dessa nyckelbegrepp i klassifikationen inte varit helt klart definierade. Avhandlingen har en huvudsakligen deskriptiv design med kvalitativ inriktning.

Studie 1. Exploring Changes over Time in Habilitation Professionals' Perceptions and Applications of the ICF-CY

Syftet var att studera hur personal i interdisciplinära team upplevde användbarheten av ICF-CY inom habiliteringsverksamhet. Urvalet utgjordes av 113 habiliteringspersonal i 14 interdisciplinära team från sex län inom Uppsala-Örebro regionen. Studien var longitudinell och data insamlades med enkäter och intervjuer vid tre tillfällen – under ICF/ICF-CY utbildning, 1 år resp 2,5 år efter. Databearbetning genomfördes med kvalitativ innehållsanalys och kvantitativ beskrivande analys. Resultatet visade bland annat att implementeringen av ICF-CY krävde anpassningar av befintliga rutiner och material men att klassifikationen upplevdes användbar för kartläggning och habiliteringsplanering. Den bidrog till nya perspektiv på barnens behov och ökade fokus på delaktighet.

Studie 2. Identifying Child Functioning from an ICF-CY Perspective. Everyday Life Situations Explored in Measures of Participation

Syftet var att identifiera vardagssituationer baserat på innehållet i kartläggningsinstrument fokuserade på delaktighet. Studien utfördes med strukturerad litteratursökning med fokus på artiklar om mätinstrument för barn med funktionsnedsättning. Items i instrument med ett identifierat fokus på delaktighet länkades till ICF-CY koder för att möjliggöra jämförelse och analys av innehållet i relation till vardagssituationer. Tre vardagssituationer identifierades för barn i alla åldrar. Det framkom en skillnad mellan vardagssituationer för förskolebarn i förhållande till tonåringar.

Studie 3. Professionals' Views of Children's Everyday Life Situations and the Relation to Participation

Syftet var att identifiera vardagssituationer baserat utifrån de professionellas perspektiv. Ett annat syfte var att jämföra hur vardagssituationer och delaktighet uppfattades relaterat till ICF-CY kategorier inom komponenten Aktiviteter och Delaktighet. Studien hade en 'concurrent mix methods design'. Urvalet utgjordes av 297 habiliteringspersonal och studenter på avancerad nivå i Sverige, USA och Portugal. Data samlades in med en öppen fråga angående barns vardagssituationer parallellt med en enkät angående bestämning av begreppen delaktighet respektive vardagssituationer. Svaren på den öppna frågan länkades

till ICF-CY koder. Data från de två datainsamlingarna integrerades. Elva vardagssituationer identifierades, delvis andra än de som identifierats i studie 2. Det framkom en skillnad mellan vardagssituationer för förskolebarn, skolbarn, och tonåringar samt en viss skillnad vad gäller deltagarnas uppfattning beroende på arbetsområde och kulturell bakgrund. Svenska deltagare tycktes mera fokuserade på barns fungerande i vardagssituationer jämfört med de övriga som mera fokuserade på testsituationer. Vad gällde relationen mellan begreppen livssituation och delaktighet, så var kopplingen starkast för kommunikation, interaktion, viktiga livsområden såsom lek, utbildning och arbete och socialt liv.

Studie 4. Applying the ICF-CY to Identify Children's Everyday Life Situations

Syftet var att integrera resultatet från studie 3 med resultatet från andra studier som genomförts under samma tidsperiod för att foga ett föräldraperspektiv till det professionella perspektivet. Tre externa studier inkluderades: en svensk studie om nätverkens perspektiv på vardagssituationer för barn med svåra funktionsnedsättningar, ett USA-kanadensiskt projekt för att utveckla ett kartläggningsinstrument fokuserat på delaktighet och omgivning samt en sydafrikansk studie för att identifiera items till ett kartläggningsinstrument för barns delaktighet i vardagssituationer. Analyser gjordes genom att länka uppgifter till ICF-CY koder. Det framkom att föräldrars och personals uppfattningar av barns vardagssituationer överensstämde när det gällde personlig vård och viktiga livssituationer men att de skiljde sig när det gällde hemliv och socialt liv. Två uppsättningar av 8 respektive 10 vardagssituationer utkristalliserades, anpassade för förskolebarn respektive för skolbarn och tonåringar.

Huvudresultat och diskussion

ICF-CY ansågs användbart som gemensamt ramverk för tvärvetenskapliga rehabiliteringsteam, främst för kartläggning och rehabiliteringsplanering. Det krävdes dock tid och anpassningar av befintliga rutiner för att klassifikationen skulle bli implementerad i dagligt arbete. Processen hade sannolikt påskyndats om dessa anpassningar varit klara i förväg.

Vardagssituationer relaterades till de sena ICF-CY kapitlen d3-d9 med dominans för personlig vård (d5) och viktiga livssituationer (d8). En trolig

förklaring till att de två första kapitlen, vilka avser lärande, tillämpande av kunskap och barnets hanterande av allmänna uppgifter och krav, inte jämföras med en vardagssituation beror troligen på att de utgör förutsättningar för delaktighet inom övriga områden. Två uppsättningar med tio vardagssituationer bestämdes för yngre (0-6 år) respektive äldre barn (7-17 år). De skiljde sig genom att fokusera på milstolpar i barns utveckling för yngre och på sociala aktiviteter för äldre barn. Det var tydligt att föräldrar framhöll hushållsgöromål och socialt liv i högre grad än de professionella. För barn med funktionsnedsättning utgör dessa vardagssituationer goda tillfällen för föräldrar att stimulera sitt barns utveckling i naturliga situationer och miljöer, vilket är en fruktbar strategi jämfört med att professionella implementerar strukturerade träningstillfällen i hemmet.

Grundat på de professionellas utsagor, bedömdes relationen mellan livssituation och delaktighet starkare ju mer komplext och situationsbundet som innehållet i ett aktivitets-/delaktighetskapitel var. När det gällde fördelningen av 'aktivitet' respektive 'delaktighet' över kapitlen, tydde resultatet på en delvis överlappning mellan aktivitets- och delaktighetskapitlen, vilket var i överensstämmelse med alternativ 2 i ICF-CY, samt att tidiga kategorier inom kapitlet var tillämpliga för yngre barn och de senare för äldre. I samband med att data länkades till ICF-CY koder, uppmärksammades behov av länkingsregler utöver de ICF regler som fanns beskrivna. Det uppmärksammades också att aktiviteten 'att sova' saknas och att det föreligger ett behov av mindre justeringar inom klassifikationen för att missförstånd ska undvikas. Rekommendationer kring detta samt kring implementering och användning av klassifikationen i kliniskt arbete presenteras i slutet av avhandlingen.

De två uppsättningarna av vardagssituationer kommer att ligga till grund för fortsatt arbete för att identifiera innehåll i code sets. Det är också viktigt att barn och unga själva får komma till tals, dels för att fastställa vilka vardagssituationer som är viktigast men också för att bestämma rubriker som speglar deras uppfattning om det som förekommer i vardagen och för att diskutera innehåll i code sets.

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Together we heard about the ICF (at that time presented as ICIDH beta version) in the evening of February 5, 1998 and I made my first acquaintance with professor Rune J Simeonsson from University of North Carolina at Chapel Hill (UNC-CH), later also professor at Jönköping University. I must admit, that the classification and all its constructs confused me but my boss at that time, Ann-Sofie Holmberg, became intensely engaged and pushed me into the ongoing trials. Thank you Ann-Sofie, you made me a

favor and your confidence in me strengthened my self-esteem and helped that I finally dared to take the step into the academic world.

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Despite challenges like this and like an Italian ICF Training programme ingoing in the EU-MHADIE project, my motivation grew to research on my own. A stop on the journey was the matter of money and once again, my gratitude is directed towards Eva and Mats and their support. The application became successful and they opened the doors to the Mälardalen ISB corridor for me, giving me the favor to go on working with the 'CHILDers' Agneta, Anna, Anne, Jenny, Lena, Lilly, Maria, Martina, Nina, Regina, and the rest of you – thanks for an unforgettable time! You never ever made me feel too old for your community!

In a short while, the journey would take a different direction because as a doctoral student I belonged to the School of Learning and Communication (HLK) at Jönköping University but also to the Swedish Institute of Disability Research (SIDR). Doctoral courses at various universities made the trip go 'hither and thither' but I always felt welcomed in the corridor at HLK, thanks to Lillian Bränsvik-Karlsson and Katarina Anemyr who have been department managers during these years. However, my academic everyday life had been so much lonelier and more frustrating without local friends. Marita Falkmer, at the moment living on the other side of the globe, Ann Simmeborn-Fleischer, Ylva Ståhl, Anna-Karin Axelsson, and more: you have no idea of how much you have meant to me – thanks for everything!

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