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PARTICIPATION IN LEISURE ACTIVITIES OF CHILDREN AND YOUTHS WITH AND WITHOUT DISABILITIES

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ABSTRACT

The World Health Organization (WHO) defines participation as a person's involvement in a life situation, and to participate in leisure activities is one of the most important aspects of health and well-being. When a child is involved and engaged in a leisure activity, it gives the child a sense of belonging, opportunities to make friendships, and possibilities to develop physical and social competences and skills. Children with disabilities tend to be restricted in their abilities to participate in leisure activities due to mobility problems, communication disorders, and pain, but also as a result of negative attitudes from others and problems with transportation and accessibility.

Knowledge of the personal and environmental factors that facilitate or hinder participation in leisure activities for children with disabilities is essential to be able to implement successful interventions with the aim of increasing participation.
This requires a valid assessment of participation that can give both an objective and subjective view of the multidimensional construct.

The overall aim of this doctoral thesis is to describe and compare patterns of participation in leisure activities of children with and without disabilities by cultural validation and use of the Children's Assessment of Participation and Enjoyment/Preferences for Activities of Children (CAPE/PAC) in the Swedish context. A specific goal is to develop and implement a client-centred model of intervention with the aim of improving participation in leisure activities by children with disabilities.

The result from Study I showed that the slightly modified Swedish version of the CAPE was valid for Swedish children. The outcome of standardized mean diversity score was significantly higher compared with the outcome of the original version of the CAPE, indicating that validation of the item relevance in the new context was necessary. The overall findings in Study II indicated that Swedish children with disabilities participated in a higher diversity of leisure activities, but with less intensity, compared to children without disabilities. Study III showed that there are differences between countries in patterns of participation in leisure activities for children with disabilities in regards to both diversity and intensity. For children without disabilities there were only minor differences between the countries. The results of Study IV showed that a designed intervention approach could be applied in the clinic for increasing participation in leisure activities by children with neuropsychiatric diagnosis.

The overall clinical implications and conclusions from this thesis are three-fold. First, a cultural validation of the CAPE/PAC is necessary when surveying Swedish children's participation in leisure activities. Second, the patterns of participation in leisure activities of children with and without disabilities differ both nationally and internationally, and this provide evidence of the need for changes in national legislations, policies, and therapeutic approaches that promote participation of children with disabilities. Third, an intervention model with a client-centred approach in which children with disabilities define their own leisure activity goals by using the CAPE and PAC appears to be effective in increasing participation in leisure activities.

LIST OF PUBLICATIONS

I. Ullenhag A, Almqvist L, Granlund M, Krumlinde-Sundholm L. Cultural validity of the Children's Assessment of Participation and Enjoyment/Preferences for Activities of Children. Scandinavian Journal of Occupational Therapy. 2012; 19 (5): 428-38.

II. Ullenhag A, Krumlinde-Sundholm L, Granlund M, Almqvist L. Differences in patterns of participation in leisure activities in Swedish children with and without disabilities (Submitted).

III. Ullenhag A, Bult M.K, Nyquist A, Ketelaar M, Jahnsen R, Krumlinde-Sundholm L ,Almqvist L, Granlund M. An international comparison of patterns of participation in leisure activities for children with and without disabilities in Sweden, Norway and the Netherlands. Developmental Neurorehabilitation, 2012; 15 (5): 369-85.

IV. Ullenhag A,Granlund M, Almqvist L, Krumlinde-Sundholm L. Intervention to increase participation in leisure activities for children with neuropsychiatric disabilities (Submitted).

CONTENTS

LIST OF ABBREVIATIONS

CAPE/PAC	Children's Assessment of Participation and Enjoyment/ Preferences for Activities of Children
CP	Cerebral pares
GAS	Goal Attainment Scaling
GMFCS	Gross Motor Function Classification System
ICF	International Classification of Functioning, Disability and Health
ICF-CY	International Classification of Functioning, Disability and Health-Children and Youths version
ICIDH	International Classification of Impairments, Disabilities, and Handicaps
WHO	World Health Organizations

1 INTRODUCTION

1.1 ABOUT THE THESIS

Participation in leisure activities is one of the most important features of functioning and well-being. Leisure activities are often intrinsically motivated, which is a longing to do something because it is enjoyable and interesting (1). Through such intrinsically motivated activities, children often experience a sense of flow, an intense absorption, and a high level of persistence (1-3). Positive leisure engagement will give the child the opportunity to fulfil personal interests, make friendships, and develop self-identity (4, 5). Participation in leisure activities will also contribute to development of physical function, social skills, and normal behaviour, all of which are promoted by interactions with family members, adults, and peers (2, 5-9). Promoting participation in enjoyable leisure activities requires that the environment must be accessible and supportive of the child's autonomy (1-3).Such an environment is often difficult to attain with children with disabilities, so it is important to study how such environments can be created for this population.

Children with disabilities tend to have a lower frequency of participation in leisure activities than children without disabilities due to personal and environmental barriers such as lower autonomy, mobility problems, negative attitudes of others, and limited accessibility (10-14). To identify obstacles to participation in leisure activities, valid and reliable assessments of all aspects of the multidimensional construct participation are essential, and a self-reported instrument of participation is the preferred method for understanding the often subjective view a child has of their own levels of engagement and satisfaction (15). The use of such an instrument, along with instruments measuring personal and environmental factors that influence participation, may allow service providers to identify strategies that facilitate participation among children with disabilities, including physical and social functions, accessibility, availability of transportation, and community programs (8). Based on information about the child's current pattern of engagement and desire for further participation in leisure activities, interventions can be designed to increase leisure participation. Ideal interventions strengthen the child's self-efficacy and encourage the child to participate in various environments based on individually set goals (3, 8, 16, 17).

The overall aim of this doctoral thesis is to describe and compare patterns of participation in leisure activities by children with and without disabilities. The thesis begins by defining disability and leisure activities and then defines the theoretical framework of the construct of participation. Factors that influence participation are then described.

As a first step towards fulfilling the aim of this thesis, the Children's Assessment of Participation and Enjoyment/Preferences for Activities of Children (CAPE/PAC) assessment instrument is culturally validated for Swedish children. How to best validate an assessment instrument of participation will be discussed in relation to the suitability of using classic psychometric approaches and modern test methodologies, such as the Rasch measurement model, for the validation. Clinimetrics is suggested as an alternative approach.

In a second step, the CAPE is used along with additional information to map factors related to participation in leisure activities by children in general as well as for children having mainly physical disabilities in Sweden, Norway, and the Netherlands.

Finally, in a third step the results from the first two steps are used to pilot test a client-centred model of intervention with the aim of improving participation in leisure activities by two children with neuropsychiatric diagnoses. The content and feasibility of this client-centred model and the challenges in measuring participation as an outcome will be further described and discussed in subsequent sections of this introduction.

1.2 DEFINITION AND PREVALENCE OF DISABILITY IN SWEDISH CHILDREN

Disability is the umbrella term for impairments, activity limitations, and participation restrictions. The disablement process is the interaction between persons with impairments and the attitudes and environmental obstacles that hinder these people's full and effective participation in society on an equal basis with others (18, 19). This means that 'disability' is not necessarily an attribute of the person, and people with the same disorder can experience different degrees and types of limitations depending on the context. The United Nation (UN) Convention defines people with disabilities as "those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (18, 20). This definition has evolved from a social-political perspective that views disability as a political issue and a matter of basic civil rights (21, 22). People with disabilities need human rights protections guaranteed in law that are fully integrated into political and social policy. For example, if a child in a wheelchair cannot get in to the bowling hall, because there are steps to enter, the social-political viewpoint suggests that the problem does not lie in the child's impairment, but in the construction of the building. The 'social-political' perspective emerged as a reaction against the so-called 'medical model' in which disability is defined as a result of a disease or trauma and observed as a deviation from biomedical norms (21, 22). These new ways of thinking about people with disabilities have accelerated and contributed to the development of the WHO's International Classification of Functioning, Disability and Health (ICF) (23).

Article 23 of the UN Convention on the Rights of the Child (CRC) focuses specifically on children and young people with physical or mental disabilities, and aims to give these children the same rights to be treated with respect and to be heard as apply to all children in the world. Sweden ratified the Convention in 1990 (24). The CRC contains four principles. The first principle states that no child should be discriminated against and that all children should have equal dignity and rights. The second principle states that the child's best interests should always be the focus of all actions relating to the child. The third principle states that each child's right to life, survival, and development includes not only the child's physical health but also the child's spiritual, moral, and social development. The fourth principle states that children should have a full life and actively participate in society, and that the child has the right to form and express their views and have them taken into account in all matters affecting him or her (24).

Because the definition of disability is not totally clear and different research methods use different criteria, the number of children having one or more disabilities often varies in surveys on health and welfare. It is estimated that 3–5% of Swedish children between the ages of 3 and 18 years have one or more disabilities that need action by the county council's specialist units (25). Riksrevisionsverket (the Swedish national audit office) provides statistics indicating the number of Swedish children with disabilities. These statistics show that about 50 000 children between 0 and19 years old receive some form of support from municipalities, county councils and the financial support provided by the Social Insurance (26). Furthermore, in 2009 there were 19 752 children and young people 0-22 years old who had received at least one benefit from the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS), a law that sets out rights for persons with considerable and permanent functional impairments (26).

Common disabilities in Swedish children involve vision, hearing, motor skills, language, cognition, attention, and ability for interaction and communication, and are usually divided into visual and hearing impairment, physical disability, language disorders, mental retardation, and neuropsychiatric disorders. It is not unusual that a child may have a combination of different disabilities. In this thesis, the samples of children with disabilities have disorders mainly related to the central nervous system and/or musculoskeletal or neuromuscular problems.

Children with cerebral palsy represent the largest group of children with severe physical disabilities with a prevalence of 0.22% (27). The rate of spina bifida among newborns is 0.029% (28), 0.025% of children have multiple disabilities, approximately 0.07% children have muscular disorders (25) and 2.9 per 1000 newborn infants are reported to have plexus injury (29). Almost 1-2% of all children have a minor learning disability and 2.9 per 1000 are reported to have severe mental retardation (30). The prevalence of Attention Deficits Hyperactive Disorder is 2-3% of children in primary school (31), and 0.6 to 1.0% of children have autism or an autism spectrum disorder (32).

1.3 LEISURE

Leisure can be defined in three ways: leisure as time, leisure as activity, and leisure as a state of mind. *Leisure time* is the time free from obligations at work or at school that allows for engagement in activities that the individual finds enjoyable, relaxing, competitive, etc (5, 6, 33-35). *Leisure activity* can be defined as an activity that an individual freely chooses to participate in out of school or work (5, 35), and can be differentiated into formal or informal activities. The former involves organized activities that are time scheduled and led by a leader or supervisor, and the latter involves activities that require little or no planning and refers to play or social activities that are initiated by the individual (5, 36, 37). There is no clear definition of what a leisure activity is because what may be a leisure activity for one person, for example gardening, may not be a leisure activity for another. Whether an activity is leisure has more to do with the person's state of mind than what is objectively defined as a leisure activity. *Leisure as a state of mind*, therefore, is a subjective experience of the activity including intrinsic motivation, freedom to do what one likes, and a sense of pleasure and control (35). The person's perceived competence in the activity is also crucial and relates to the feeling of satisfaction when participating in a leisure activity. The

person's skill level must be in accordance with the required challenge of task performance for the person to feel enjoyment and satisfaction while participating in a leisure activity (1, 38, 39). The definitions of leisure used in this thesis are associated with *leisure activity*, an activity that is freely chosen to participate in out of school, and *leisure as a state of mind*, the subjective experience of the activity.

Participation in joyful leisure activities can improve a child's well-being, promote physical and mental health benefits and stimulate the development of personality and of age-appropriate social manners. Several factors have been identified in earlier research that influence the child's participation in leisure activities, such as age, gender, self-efficacy, physical, cognitive and social abilities, accessibility of facilities, cost, parents preferences of activities, sense of belonging, socioeconomic variables, attitudes of peers and geographic living area. (7, 37, 40-44)

School-aged children participate in leisure activities outside of school hours and, depending on the child's age, gender, nationality and socioeconomic background, these activities occupy up to half of a child's waking hours each week (2, 6). However, research indicates that children's autonomy in how they would like to spend their free time has become more restricted (4). Children tend to spend more time in organized indoor leisure activities supervised by adults and less time in self-directed play free from adult control (6, 45-47). This might restrict the child's intrinsic motivation, creativity and autonomy (4, 6). Consequently, there needs to be a balance between the child's participation in organized leisure activities and informal unstructured play, where children are free to enjoy themselves and do as they wish without adult control (4, 6). Children with disabilities often encounter further boundaries to leisure and playful activities such as over protective parents, play conditions that are not accessible or support playfulness, outdoor play that is too physically challenging, and negative attitudes of peers (5, 48-51)

Children's leisure time can provide windows of opportunity for the promotion of function and well-being. For therapists working with children with special needs, leisure activities can be part of the rehabilitation process by facilitating the child's child's therapeutic goals (2). Research indicates a need to study the participation of children with disabilities in structured and unstructured leisure activities.

1.4 PARTICIPATION

1.4.1 Definition

The study of participation in leisure activities requires that the concept participation is defined. The WHO defines participation as a person's involvement in a life situation. This definition has been criticized, however, for not providing information about what involvement it refers to or what life situations should be included (8, 52-54).
The definition is related to being included and accepted when taking part in an area of life and that a person has the needed resources to participate and a sense of belonging (55). Within the context of health the definition of participation also includes being able to control your own life and being autonomous. Perenboom and Chorus have also included in the definition not only the actual performance of a task, but also the fulfilment of personal goals and societal roles (56). In a conceptual analysis of participation by Hoogsteen and Woodgate, it was concluded that to participate "children with disabilities must be involved in something or with someone, they must feel a sense of inclusion, they must have a choice or control over what they are taking

part in, and they must be working toward a goal or enhancing their quality of life" (p. 335) (8).

In the effort to define the construct of participation it is important to be clear about what participation is not. Participation is not the environment around the person even though the environmental setting will have an impact on their participation (15, 54). Furthermore, participation is not the same as activity, although in the ICF there is not a clear distinction between the two concepts. Finally, participation is not equal to quality of life (15, 53, 54). Although some authors have stated that the subjective experience of participation is the same as life satisfaction, measures of the construct quality of life tend to contain a range of different items concerning body function and activity performance when linked to the ICF and some measure proxy quality of life in ways not in accordance with the definition of participation in the ICF (15, 57). Others define quality of life as a person's subjective feeling about their life, whereas a person's participation is an objective account of what the person does (58). In this thesis the construct of participation has been defined to include two dimensions, an objective dimension (frequency of being there, related to availability and accessibility) and a subjective dimension (sense of belonging, engagement and satisfaction when being there).

1.4.2 Participation in leisure activities

Participation in informal and formal leisure activities such as play, entertainment, sports, hanging out with friends, religious expressions, music, and art can promote a child's health and well-being (5). Being active and engaged in intrinsically motivated leisure activities that are freely chosen is considered to be an essential part of children's development (5, 33). Through participation in leisure activities, children have opportunities to develop a self-identity, express creativity, and simply find enjoyment in life (5, 7, 59, 60). Furthermore, involvement in leisure activities will stimulate and support children in developing physical and social skills and competences, and help them to form social networks and friendships and maximize educational outcomes (5, 7, 59, 60). Additionally, participation can provide children with a sense of belonging that contributes to their quality of life (61). Being active in physical leisure activities will stimulate tolerance against stress and depression, increases cardiovascular and respiratory functions, facilitate musculoskeletal function, improve fitness, and promote self-esteem (4, 60, 62-64). When children have the opportunity to experience a broad range of leisure activities, it enables the development of self-identity and helps them to find activities they prefer to be engaged in (42). Consequently, without opportunities to be involved in leisure activities children are unable to explore their emotional, social, intellectual, communicative, and physical potential and are less able to grow as individuals (5) .

1.4.3 Assessing children's participation

The WHO's ICF provides a multidimensional framework for documentations, comparing and classifying the concepts of health, functioning, and disability and includes participation as a key construct (55). The development of the ICF was influenced by political, ideological and medical developmental trends (21, 22, 65) and is a further development and revision of the earlier WHO International Classification of

Impairments, Disabilities, and Handicaps (ICIDH) from 1980. The revision of ICIDH was based on a paradigm shift from a medical perspective of human functioning, where disability can be seen as a consequence in daily life of having a physical impairment, to a more social perspective of disability (21, 65-68). The social perspective views disability "as a loss or limitation of opportunity to participate brought about by social and physical barriers" (p.1776) (21). Further criticisms were rasied that the ICIDH framework was too deterministic and focused on pathology without reflecting on the role of the environment in the definition of functioning (65). The revision of the ICIDH resulted in the 2001 ICF that was based on a combination of the medical and social dimensions of health and functioning as explained by a biopsychosocial model (21, 22). The 'bio' stands for body function and structure, the 'social' concept reflects participation in a life situation, and the 'psycho' describes how a person performs an activity and can be seen as a bridge between the two other concepts (22, 65).
The ICF has two levels: (1) body function and structure, including physiological and psychological functions/systems, and (2) activities, defined as executing a task, and participation, described as involvement in life. These levels are influenced by personal factors such as age and gender, and environmental factors concerning accessibility and physical, social, and attitudinal factors.

In 2007, the WHO published the children and youth version, the ICF-CY, which combines the UN Convention on Rights for Children and the ICF and considers the importance of the child's development (22). The ICF-CY provides a framework to describe limitations to children's health and functioning and to identify influencing environmental factors. In the development of the ICF-CY, considerations were taken to identify children on the basis of their functional changes over time related to the influences of environmental factors such as psychological influence of caregivers and technology dependence (22, 65, 69). In this thesis the ICF-CY has been used.

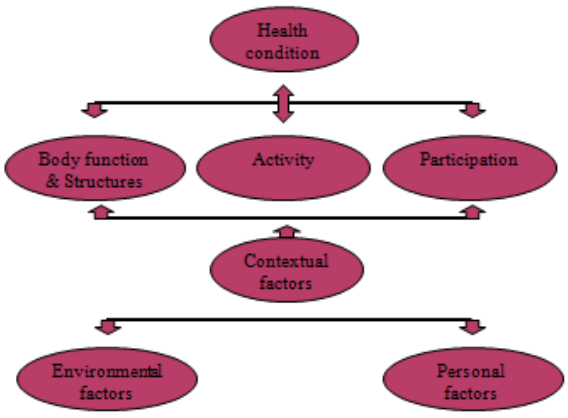

Figure 1 The International Classification of Functioning, Disability and Health model.

The component structures in the ICF (2001) and ICF-CY classification are not identical to the dimensions the ICF model (Figure 1). In the classification, the personal factors have been left out due to difficulties in obtaining consensus within the WHO on how to define personal factors. In addition, in the classification the topics of activities and

participation have been merged into one component due to difficulties in deciding how to separate activities from participation. The ICF's definition of participation, involvement in a life situation, used in the classification has been criticized for not making a clear distinction between activities and participation (53, 57, 67, 70). This conceptual issue contributes to a difficulty in measuring participation. Both activity and participation are presented as covering the same nine life areas representing aspects of functioning from an individual (activity) and societal (participation) perspective: (1) learning and applying knowledge, (2) general tasks and demands, (3) communication, (4) mobility, (5) self-care, (6) domestic life, (7) interpersonal interactions and relationships, (8) major life areas, and (9) community, social and civic life. In the literature it have been argued that the first five life areas occur at the personal level, and therefore, might be seen to cover the activity domain, whereas the other areas involve role performance at a societal level and therefore resemble participation (57, 71). Whiteneck makes a claim for a distinction between activity and participation by referring to Nagi, Wood, and Badley who see that participation occurs at the societal level and to participate is to fulfil social roles, which requires performance of many different activities depending on the specific demands from the environment(57, 67, 72, 73). Consequently, the distinction between the participation and activity dimensions in the ICF is complex, but it is argued that participation is more determined by environmental and cultural factors, whereas activity tends to be more distinct and limited by body impairments (57). For example a child can have difficulty kicking a ball (activity) due to coordination problems (body function) which will have an impact on his or her performance (participation) in the game and influence his or her role on the football team.

The activities and participation components can be operationalized either as *capacity*, "executing a task in a standardized or test situation" or as *performance*, "what the person does in his or her daily life", and these are influenced by the environment and personal factors. Consequently, participation can only be measured with the performance qualifier because participation involves a social context (15, 66, 68). The performance qualifier describes participation as equivalent to the frequency of performing an activity (53, 56, 66, 68). This *objective* dimension of participation includes whether a child has access to a setting, for example the football pitch, and the frequency of his or her attendance at football training. The objective dimension of participation can be easily quantified and measured, and will provide information on limitations to availability and accessibility for children with disabilities. These are important issues in planning for community policies, resources, and services (3, 52, 53, 66).

The *subjective* dimension of participation is not classified in the ICF or ICF-CY, but is in a footnote on p.18 and is defined as a sense of belonging, engagement, or satisfaction while attending an activity (69). Because it addresses the extent of a person's self-determination, it is not covered by the objective performance qualifier and thus is not found in the ICF/ICF-CY classification (3, 53, 56, 66). Assessments of subjective experience of participation need to capture the child's intrinsic motivation and engagement while participating in an activity (3, 8, 66, 68, 74). A child who has access to and participates in a leisure activity might not experience a sense of belonging or engagement. Consequently, researchers have stated that a third qualifier in the ICF-ICF-CY, which can measure the subjective dimension of participation, is needed (3, 66, 68). For example, if a child participates in a leisure activity that is not self-selected, for example taking a music lesson in how to play the piano when they want to play the guitar, the child may not be engaged or feel a sense of internal motivation while

participating. Maxwell et al. (2012) have compared self-reports of engagement between school activities where children have their mental focus on the activity they attending and activities where they do not. The results indicate that children's engagement is higher when their mental focus is on the activity, and indicates that a qualifier focusing on engagement adds information to what can be known from only assessing performance (75).

When measuring participation, it is essential to make clear what dimension (the objective or the subjective) is being focused on and to not draw inferences about the other aspect (53). The environment where the performance of activities takes place also needs to be considered because the cultural context can be a facilitator or a hindrance for participation depending on the social role the person wants to have/play in that environment (10, 33, 37, 76). Consequently, an accurate and useful clinical assessment of children's participation in leisure activities requires an instrument that captures all dimensions of participation, not only which activities are done and the frequency of the performance but also environmental factors and affective dimensions of participation (9, 15, 77).

Discussions about how to best operationalize and measure the complexity of children's participation in leisure activities is ongoing, and there are relatively few assessment tools of this multidimensional phenomenon (15, 53, 78, 79). Existing assessments vary in content, with some focusing on children's physical activity levels regarding frequency and diversity of participation, some on play, some on school-based activities, and some on household chores (9, 36, 79-82). No single measure of children's participation, however, seems to meet all the criteria of dimensions and life areas in the ICF/ICF-CY (15, 79). Adolfsson et al., McConachie el al., and Sakzewski et al. have reviewed and summarized measures of participation (not just assessments covering participation in leisure) applicable for children and youths by using the existing ICF chapters as a guide (15, 77, 79). In total eleven measures were identified; LIFE-H, LAQ-G, CASP, ASK, CAPE, CHORES, PIP, SFA, SOM, COPM and GAS. The identified measures are briefly described in Table 1. Because no existing assessment tool manages to capture all dimensions of participation, additional instruments need to be used when measuring this construct.

Table 1 Assessments for measuring participation defined by the ICF/ICF-CY

Assesment	Age range	Purpose	Content	ICF/ICF-CY
CAPE **	6-21 years (children with/without disabilities)	Participation	Activities out of school	All domains except self-care
SFA *	5-12 years (physical/ sensory impairment)	Activity/ participation	School-related functional tasks	All domains except domestic life
SOM *	3-18 years	Activity/ participation	School-related functional tasks	All domains except domestic life
CHORES *	6-11 years (children with/without disabilities)	Activity/ participation	Household tasks	Self-care Domestic life
LIFE-H *	5-13 years with disabilities	Activity/ participation	Social participation in daily activities	All domains
COPM **	All ages and disabilities	Activity/ participation	Dependent on goal set	Dependent on goal set
GAS **	All ages and disabilities	Activity/ participation	Dependent on goal set	Dependent on goal set
ASK **	5-15 years (physical impairments)	Participation	Frequency of participation in care mobility and leisure	Mobility, self-care, domestic life, major life area, community social life
PIP **	3-18 years	Participation	Participation in play and leisure activities.	Domestic life, major life area, community social life
CASP *	3-18 years (acquired brain injury)	Participation	Participation in home, school and community	All domains
LAQ-G *	5-7 years (children with disabilities)	Participation restrictions	Participation restrictions	Communication, mobility, self-care, interpersonal interactions, community social life

CAPE: Children's Assessment of Participation and Enjoyment; SFA: School Function Assessment; SOM: School Outcome Measure; CHORES: Children Helping Out, Responsibilities, Expectations, and Support; Life-H: Assessment of Life habits of children; COPM: Canadian Occupational Performance Measure; GAS: Goal Attainment, Scaling; ASK: Activities Scale for Children; PIP: Paediatric Interest Profiles; CASP: Child and Adolescent Scale of Participation; LAQ-G: Lifestyle Assessment Questionnaire. * proxy responded, ** child responded.

Assessments of children's participation in leisure activities must also capture differences across gender and children's age intervals because the child's patterns and preferences for activities differ between the sexes and change over time (9, 12, 40, 83, 84). Further, it is essential that the assessment is user friendly, fairly short, and easy for the child to complete independently. To be able to measure the subjective aspect of the child's engagement and satisfaction with participation, the child needs to respond to questions about his/her participation and self-reported instruments are, therefore, preferred (15, 57). Additionally, it is crucial to assess the impact of environmental factors that support or hinder participation in different contexts, school, home and the community, but also across environments that differ in culture, geography, and services (85).

Because the concept of participation is multidimensional and influenced by many different factors, the construct cannot be captured using one single scale (52, 78). Instead different subscales all including important factors influencing the construct are more applicable when measuring participation. The multidimensionality of the

construct will have implications in the development and validation of participation measures (52). Studies have shown that cultural differences between and within countries, such as variations in services and school systems, legislations, laws, traditions, geography, and religion are associated with differences in leisure activity patterns of children with and without disabilities in different European countries (41, 58, 80, 85)

Thus before using an assessment in a new condition, a cross-culture validation is essential. In the literature there are some recommendations and guidelines for cross-cultural adaptations of assessments involving five types of equivalence.

(1) *Conceptual equivalence* refers to whether children in different cultures see participation in leisure activities in the same way. This can be investigated by literature reviews, focus group interviews, and consultation with experts (86-88),
(2) *Item equivalence* is related to whether the specific item is relevant for the population of children and is established in the same way as conceptual equivalence (86, 88),
(3) *Semantic equivalence* includes a careful translation of the instrument to ensure semantically equivalent items. Guillemin recommends that translation should be done by at least two independent persons into their native tongue. Thereafter a back-translation is recommended. Finally, an expert group should review the two versions (86, 89),
(4) *Operational equivalence* determines if the same scales, instructions, and administration of the instrument are applicable in different cultures (86, 89).
(5) *Measurement equivalence* examines whether the psychometric aspects of validity and reliability produce interpretable results (86, 87, 89-92)

A psychometric approach is commonly used to decide which items are to be eliminated or retained in the test, and an examination of the correlation between each item and the full scale is recommended (91-93). Low correlations, indicate that either the item or the scale may not measure the intended construct (91, 93). The goal of an instrument is to measure one thing or one construct, and one way to demonstrate that this is the case is to evaluate the level of internal consistency reliability (the coefficient alpha). The internal consistency refers to the overall degree to which the items are correlated, and items should be retained on the basis of their correlations with the overall construct, (92, 93). To improve the internal consistency, removal of poor items which have low total item correlations or low correlation with other items can lead to an increased coefficient alpha (91). Another psychometric method is factor analysis that can be used to explore or confirm if groups of items contain a single construct, multiple components of a single construct, or different constructs (91-93). Factor analysis is useful in deciding whether a group of items hypothesized to assess a construct cluster together when they are analysed with items from other scales, and whether such items within a measure describe a unidimensional or a multidimensional construct (92).

An additional approach to modifying an assessment instrument is to use modern test methodologies, such as the Rasch measurement model. The Rasch model requires that items and persons' response patterns fit the unidimensionality of the construct and provides information about the hierarchies among items and respondents (52, 88, 90). With Rasch analysis, it is also possible to calculate if the items are misfit. Misfitting items are items that are not related to the rest of the scale or may not add any new information to the construct (88, 90, 91).

However, a prerequisite for applying the Rasch model is that the construct measured should be seen as a hierarchy of a person's abilities, ranging them from less to more able, and a hierarchy of item difficulty ranging from easier to harder. These requirements are difficult to fulfil when measuring participation.

A clinimetric approach may be an accessible way to validate a measurement of the participation phenomenon. Clinimetrics was developed in clinical medicine by Feinstein with the aim of providing a broad global rating of clinical phenomena (52, 57, 94-96). The difference between psychometrics and clinimetrics is that in psychometrics all items are assumed to be the effect of the construct and the aim is to develop one scale that measures single characteristics or attributes (52, 97). In clinimetrics different items are assumed to be causal indicators reflecting several characteristics that together define a construct (52, 96, 97).

1.5 FACTORS INFLUENCING CHILDREN'S PARTICIPATION IN LEISURE ACTIVITIES

As mentioned earlier, children's participation in leisure activities is influenced by many different personal and environmental factors. The personal factor, age has been demonstrated to influence the patterns of participation in leisure activities. Younger children tend to perform a higher number of leisure activities, especially recreational activities that often are done at home together with the family. Increasing age is related to less diversity and intensity in participation except for participation in social activities, which tend to increase (12, 13, 17, 37, 40, 84, 98, 99). Furthermore, the personal factor, gender also have an impact on the preferences of activities. Boys are more likely to prefer to be involved in physical activities, whereas girls are often more interested in social, skill-based, and self-improvement activities (12, 13, 33, 34, 38, 40-42, 50).

Another personal variable associated with participation in leisure activities is the child's intrinsic motivation. Intrinsic motivation is the desire to do something for its own sake because it is enjoyable and interesting (1, 100) and is related to the child's self-efficacy. When the child has competence and skills to perform a leisure activity that is self-selected and sufficiently challenging, it will strengthen the intrinsic motivation. Self-efficacy refers to personal beliefs of how well one expects to perform an activity and is closely linked to the mastery of experiences, i.e. when one experiences performing a task successfully, one's sense of self-efficacy is strengthened (101). Children with stronger self-efficacy choose to participate in more challenging leisure activities than children with lower self-efficacy. According to the niche concept, which can be seen as a situation or activity specifically suited to a person's interests, abilities, or nature, children tend to seek out niches that are congruent with their talents and interests (102). Consequently, children who have positive experiences from involvement in a specific leisure activity may elect to participate in similar activities because the mastery, motivation, and pleasure in learning new things increases the level of participation in those activities (84, 102). Additionally, negative attitudes of peers and a low self-efficacy can contribute to the child not seeking out their preferred niches.

Studies have indicated an association of direct and indirect environmental factors that influence the child's patterns of participation in leisure activities. In the bio-ecological model by Bronfenbrenner, the micro-environment is the child's immediate

setting in which they have regular interactions with for example, family, friends and teachers (103). A child can have many different micro-environments, and this number will increase with age. The persons involved in the child's direct micro-environment will influence the child's participation with their own strengths and weakness, for example, the parents' own propensities for physical, social, and cultural activities, parental education, and levels of parental stress (5, 13, 42, 43, 84, 103). Having parents with higher interests in leisure activities, who have a higher level of education and a lower level of stress, a higher economic standard, and living with two parents are all factors associated with a higher level of participation in leisure activities, especially in formal structured activities that often require special equipment andmember fees (37, 40, 41, 43, 98, 104).
The interaction between the child's different micro environments, for example the communication between the football coach and the parents, is called the mesosystem and also influences the child's patterns of participation(103). The exosystem is the system that influences the child's participation indirectly, for example, if a parent had to work full time and had a long commute, he or she will not be able to take the child to leisure activities in the afternoon. Finally, the macrosystem is the system that is farthest away from the child and influences the child's participation even more indirectly. The macrosystem consist of cultural traditions, laws, school, and health services provided by organizations or the government that influence the child's indirect and direct environments (103). The structure of the macrosystem will thus have a large impact on the child's accessibility and availability of transportation, assistive technology, childcare, and education, all of which influence the child's participation in leisure activities (84, 105-108).

Another environmental factor of importance is the population density of the child's living area. The time spent outdoors engaging in leisure activities is dependent on the availability of safe play areas in close proximity to the child. Children and adolescents from rural districts tend to spend more time participating in outdoor games, sports, and domestic chores, especially during the warm season, because living in a rural area is characteristically associated with more available space and safer neighbourhoods. Children in urban areas, on the other hand, tend to spend more time in organized sports in designated play areas or specialized institutions where they are often transported by an adult to play and be physically active (43, 109-111).

The way in which children spend their leisure time may also vary across countries and be influenced by differences in municipal resources, public services, and societal and parental expectations (58, 80, 105, 106). In a review of how children and adolescents spend time across the world, Larson and Verma reported that children from the USA and Western Europe spend between 18-86 minutes each day in sports compared to only 4-7 minutes each day for Asian children. Moreover children in non-literate settings, e.g. in a rural village in Kenya, spend less time (20 min per day) in leisure activities than children in literate societies (e.g., Japanese children, 80 min per day) due to household chores and work (85).

The development of the child and the level of participation can be seen as a result of the interaction between the child and the different systems in the bio-ecological model. By participating in different activities, in diverse contexts, and with various people, the child is able to develop age-appropriate physical skills and social competences (103, 112). The personal and environmental factors mentioned above will have an impact on both children with and without disabilities, but children with disabilities tend to have greater restrictions and barriers to their participation

associated with their disability (5, 10, 17, 37, 49, 113, 114). Pain, mobility problems, communication disorders, intellectual disabilities, and problems with social skills are examples that can reduce participation in leisure activities (10-14). Discriminating attitudes and negative reactions toward children with disabilities also constitute hindrances for participation in leisure activities (50, 105, 115, 116). Further, psychosocial barriers that influence the child's participation include a sense of being different from peers, problems taking a leading part in games and play, and difficulty in understanding the social norms when joining a group (50, 105, 115, 116). Studies have also shown that children with mental and physical disabilities tend to have lower levels of motivation and prefer less complex tasks during play than children without disabilities (117, 118). Other obstacles for children with disabilities are outdoor play areas with equipment that is not accessible for children with disabilities, and parents who need to accompany and assist children in their leisure activities and who sometimes can be over-protective and limit the child's autonomy and play opportunities (34, 49, 115, 116).

As a consequence of these obstacles, children with disabilities tend to be engaged in more solitary, quiet recreational activities and in more informal leisure activities that are often home-based and organized by adults compared to children without disabilities (10, 13, 36, 37, 84, 114, 119). Besides, studies have shown that children with disabilities have fewer "best" friends and it has been reported that 50% of children with neuropsychiatric disorders have problems in peer relationships that have a negative impact on participation in social activities (120, 121). In the study by Rigby and Gaik, it was shown that there was a lack of playfulness for children with disabilities and 65% of their play settings were in school, community-based settings, and at home (84, 115).

Rehabilitation services for children with disabilities are positively associated with the intensity and number of different activities children with disabilities take part in (10, 34, 122). Children that continue to participate in rehabilitation services have been shown to be more likely to be engaged in activities that require certain skills (10, 34, 122). Studies have also shown that the child's mobility function is associated with the level of participation. Children with cerebral pares who have a higher motor function ability, GMFCS level I-II had a higher level of participation than children with lower motor function level III-V (10, 14, 58, 84, 122, 123). In a study by McIntyre et al parents of children with disabilities ranked 'participation research' as the most important research priority after prevention of conditions for children with cerebral pares (124) .

1.6 INTERVENTIONS TO INCREASE PARTICIPATION IN LEISURE ACTIVITIES

Interventions for children with disabilities have traditionally been focused primarily on the level of impairment and the child's function (training in activities in daily living and mobility, such as gait functions) (125, 126). The treatment has often been developed to improve patterns of movement without reference to the functional contexts of the movements (127). For children with physical disabilities, rehabilitation has included attempts to inhibit abnormal postures and movements and to encourage more 'normal' patterns of movement. It is believed that a more 'normal' movement pattern will enhance functional ability and reduce limitations in daily activities and improve participation (128-130).

Therapists and researchers have argued that instead of focusing the rehabilitation of children with disabilities on 'normality', environmental adoptions and compensatory strategies may be more effective methods of rehabilitation (126, 127, 131, 132).
It seems to be important to take personality and environmental characteristics into consideration and to practice skills and functions that really matter for the child in the context of their daily lives (133). Moreover, new research has shown that parents, children with disabilities and therapists consider enhanced participation in leisure activities as one of the most important outcomes of intervention (124, 134).
The many proven health and functional benefits from participating in leisure activities support new strategies for intervention.

The personal and environmental factors that facilitate or hinder children's participation in leisure activities operate together in a complex set of relationships and are different for each child. Knowledge of which factors are most important for participation in leisure activities is essential to design effective interventions (5, 135). For example, if the child's self-efficacy is an important determinant of the child's participation in leisure activities, then interventions should focus on the child's sense of competence and mastery. On the other hand, if parents' sense of community-supported leisure activities is an important feature of their child's participation, then interventions should include information of available community-based leisure activities.

Systems theory can be applied to designing interventions of participation and is especially useful in the understanding of how participation develops and changes. Participation can be seen as a system of several constituent parts interacting with each other that making up an entirety and the stability of the system increases with the number of its parts (102). The child's temperament, interests, motivation, self-efficacy, and physical and social functions are examples of internal systems of the child that interact with external environmental systems such as supportive parents, socioeconomic status, and supportive social, physical, and institutional environments. These different systems have their own independent functions and impacts on the child's participation in leisure activities, but cannot be fully understood unless considered together in the whole system of participation (102). For intervention designs this means that the same outcome of participation can be attained through different strategies or that the same strategy may have different impact on different children (135). Theoretical models and methods that can handle complexity are needed for interventions to be able to enhance participation in leisure activities. The model needs to recognize and grasp the variations in individual participation of children and must consider the contributions of multiple influences and variability in the outcome (102, 136).

Participation in leisure activities is context-bound and varies between life situations (135). The focus of intervention may, therefore, not be on a single factor but on the interaction between personal characteristics and environmental variables, and interventions dealing with multidimensionality and individuality, quasi-experimental analytical observations, or qualitative designs seem to provide the best options (136, 137). As mentioned before, the concept of participation includes two dimensions, one objective and one subjective. Interventions based on an objective approach will include strategies focusing on the child's frequency of performing the same leisure activities as others in the same situation, and will include strategies that maximize the availability of the environment for the activity and the accessibility of the activity (3, 52, 53, 66).

Interventions with a *subjective* approach comprise strategies focusing on factors that influences the child's motivation, engagement, and self-efficacy while participating in a leisure activity (3, 8, 66, 68, 74).

According to the literature, an important feature of an intervention with the aim to increase participation in leisure activities of children with disabilities is to consider that the child is actively involved and placed at the centre of intervention. This implies that the therapists have to investigate the child's own preferences for leisure activities given the importance of being motivated and engaged in the activity (3, 8). The child needs to have control and be believed to be competent to set their own leisure activity goals and the intervention should strive to develop self-management strategies (8, 17, 138). The therapists should ascertain whether the hindrances to participation in the preferred leisure activity can be overcome (34). Moreover, it is essential for the therapist to investigate and understand the relationships between personal and environmental factors that can influence the child's participation in the development of strategies to promote participation (5, 34, 66, 136). The intervention must be tailored to the child's particular characteristics and operate over time so that positive changes have a chance to manifest (135). In considering which factors should be included in the intervention, one must look at patterns of relationships between factors that have been identified as important. Depending on which factors have been identified as crucial for participation, and these can be both within the child and on different levels of the ecological systems surrounding the child, the intervention may consist of different strategies (5). Services may include strategies concerning child-based factors such as psychosocial support, advocacy and connections with peers, and interventions that strengthen the child's self-perceptions, autonomy, and self-efficacy by practicing certain skills. Strategies can also influence environmental factors such as accessibility of playgrounds and public buildings, availability of community programs, locating community camps, sports, recreational, social, and leisure activities, wheelchair accessible transportation, activity accommodations, and awareness programs to improve knowledge, attitudes, and acceptance for people with disabilities (17, 50, 71, 81, 108, 126, 139, 140).

1.7 CLIENT-CENTRED APPROACH

To enhance a child's participation in leisure activities, it is essential to maintain the child's autonomy in the rehabilitation process (3). The principals for autonomy are respect for a person's thoughts, will, decisions, and actions (3, 141). It is recommended, therefore, that the child-therapist collaboration should be a dialogue through which the child's interests, preferences, and goals are the primary focus (3).

In planning interventions to improve participation for children with disabilities, a client-centred approach is required to respect the child's autonomy, self-determination, self-advocacy, choice making, and problem solving. In a client-centred approach, the empowerment of the child is vital. Empowerment is the belief that the help receiver, i.e. the child, has the capabilities and competence to control important life events and situations and to identify for their own important goals (3, 138, 142, 143).

The role of the therapists in the implementation of client-centred interventions is to use their skills in active listening and analysis of function and skills to obtain information about the child's preferences, physical and social ability levels and social and physical environment (144). The therapist will provide an opportunity to discuss intervention options, provide information about the different strategies for increased participation in

leisure activities, and encourage the child to find solutions to attain their goals (3). The provision of information will encourage the child's decision making and improve the autonomy, control and involvement of the child in the intervention (3). Interventions for increased participation should acknowledge the uniqueness of each child and provide flexible solutions to enhance participation while respecting the culture and values of the child and his or her family. Moreover, it is essential that the therapist educate, communicate, instruct, and inform the network around the child and to consult with other team members to find solutions for goal attainment (81). To successfully promote participation in leisure activities, the therapists need to use active and reflective listening, show empathy, share information, and learn with the child and his or her family (81).Further, the therapists need a broad, multilevel knowledge of factors that influences participation so they will know what to do and when and how to do it (81, 145). In interventions with a client-centred approach, therapists must know how to join with the child and the family and provide responsive and flexible services in accordance with changes in the child's needs, and to find a balance between what the child hopes for and what is clinically relevant and realistic (146). Studies have shown that children and families who are actively involved in the process of identifying for themselves important goals of the rehabilitation, and believe in its efficacy, have better rehabilitation outcomes (146-148).

1.8 GOAL-SETTING

Goal setting is commonly used to improve functional and social skills and competences, and to enhance participation in children with disabilities (2, 81, 126, 132, 145, 148, 149). Research has demonstrated that goal setting is effective for improving understanding, changing behaviour, increasing motivation, and improving outcomes (132, 149-151). As mentioned previously, it is essential that the child choose his or her own goals for leisure activities. The goals should be appropriately challenging and not too easy or too difficult to attain because there appears to be a relationship between performance and enjoyment. For example, being active in sports and "outperforming an equally rated opponent by a small margin would provide more positive competence information than outperforming the same opponent by a wider margin" and consequently provide more enjoyment (p. 38) (63). The balance between the challenge of the activity and the skills required for the activity needs to be well coordinated for the child to be motivated. The child's motivation associated with a certain goal can vary in intensity as a function of how much the child values the goal and expects to attain the goal (63).

Leisure activity goals for children are often related to a high level of intrinsic motivation. When a child is intrinsically motivated to do an activity, he or she will feel a state of flow where time stands still, but also a sense of enjoyment, awareness and control (1, 2, 74). In intrinsically motivated activities, the child often puts in a high degree of personal effort and uses positive coping strategies to reach the goal. In the article by Mastos et al., four components for goal-directed training are identified:1) selection of a meaningful goal, 2) analysis of baseline performance, 3) intervention/practice regimens, and 4) evaluation of outcome (149). In the process of goal-setting the child may need assistance to transform his or her wishes for leisure participation into intervention goals which need to be Specific, Measurable, Attainable, Realistic and Time specified, SMART (149, 151-154).

The analysis of the child's baseline performance is essential to determine which variables and factors limit the performance in the actual environment, i.e., if the hindrance consists of problems with transportation or accessibility to the play area, or are associated with the child's self-efficacy, social behaviour, mobility skill, etc (149). The performance analysis will provide the therapists with ideas for treatment strategies that will be appropriate for the child to achieve their goal (149). In the goal-oriented intervention, the therapist will emphasize learning situations to stimulate the child's autonomy and to encourage the child in problem solving (149). Finally, when evaluating the outcome of goal-directed intervention, the assessment must be addressed to the goal selected by the child and capable to detecting changes that are stated to be important and meaningful by the child (149).
The Goal Attainment Scaling (GAS) and the Canadian Occupational Performance Measure (COPM) are valuable instruments in enhancing child- and family-based decision making and goal attainment (81, 152, 155, 156).

2 AIMS OF THE THESIS

The overall aim of this doctoral thesis is to describe and compare patterns of participation in leisure activities of children with and without disabilities by culturally validating and using the Children's Assessment of Participation and Enjoyment/Preferences for Activities of Children, CAPE/PAC. Furthermore the objective is to develop and implement a client-centred model of intervention with the aim of improving participation in leisure activities in children with disabilities. The specific research questions of the thesis are outlined below:

-Is the construct of participation as operationalized in the CAPE measure comparable across nations?

-How do generic and disability-specific factors influence the patterns of participation in leisure activities, as measured with the CAPE, in children with and without disabilities nationally and internationally?

- How effective is a client-centred intervention model in enhancing participation in leisure activities by children with disabilities?

3 METHODS

3.1 METHODOLGICAL CONSIDERATIONS

When studying the patterns of participation in leisure activities in children with and without disabilities, it is important to use a valid and reliable instrument able to measure all components included in the construct. Consequently, an accurate and useful clinical assessment of children's participation in leisure activities requires an instrument that captures both the objective and subjective dimensions of the child's participation in leisure activities. The instrument must be self-reported and easily handled by a child to grasp the child's perspective on participation. Because there are no such Swedish instruments for assessing children's participation in leisure activities available, a cultural validation of an existing instrument from Canada, the Children's Assessment of Participation and Enjoyment/Preferences for Activities of Children (CAPE/PAC), was required.

By following the recommended steps for cross-cultural adaptations of assessments, group interviews with children with and without disabilities and parents were conducted to establish conceptual and item equivalence (87, 88, 91, 93). Additionally, a careful translation of the instrument to ensure semantic equivalence was performed by following Guillemin's recommendations (89). Finally, the measurement equivalence, concerning whether the psychometric aspect of validity and reliability properties yields interpretable result, was established in a field test of the adapted Swedish version and by statistic analysis (87, 88, 91, 93). Because participation is a multidimensional construct with hypothetically low intercorrelation between items in the construct, a classic psychometric method did not seem to be applicable for use in the cultural validation. Instead, a clinimetric approach was used to decide which items should be included in the measure.

Because children's patterns of participation in leisure activities are influenced by several personal and environmental factors, analysis methods of the child's patterns of participation must be able to handle multifactor variance. Multiple regressions can be used to explore correlations between a dependent and several independent variables, and can provide information about the model as a whole and how much each of the independent variables can explain a particular outcome and which variable is the best predictor (157). In this thesis, multiple regression analysis was used to investigate important predictors of children's participation in leisure activities.

When implementing a client-centred intervention model with the aim of increasing participation in leisure activities in children, a single-subject AB design is used. In this design 'A' representing the baseline (non-treatment condition) and ,B, refers to intervention administration (treatment) (158).The single-subject design is believed to provide a more detailed insight into the individual child's patterns of participation than survey data or a random control study (136). Moreover, single-subject studies have also proven to be sufficient designs for use as the first step in developing and testing a new intervention (159). In the sections below, a brief study outline will be given followed by details on participants, the recruitment process, data collection, and descriptions of the assessments, methods, and statistical analyses.

3.2 STUDY OUTLINES AND DESIGN

Study I

A cross-cultural validation of the CAPE for Swedish children was performed to determine if the activity items in the CAPE were valid for Swedish children and if any relevant activities were missing. In a license agreement approved by the publisher, a translation and a back translation of the CAPE was performed individually by three persons from two research teams and a professional translator in accordance with recommendations in the literature.

In total, 13 group interviews were conducted with 51 children without disabilities and 15 children with disabilities of the ages 6–15 years. Two group interviews with parents to children with and without disabilities were also held. Three researchers matched the leisure activities generated from the group interviews to the original activities in the CAPE. Sixteen leisure activities could not be fit into the original version of the CAPE and were added to the original version. The modified trial version of the CAPE was tested on 337 Swedish pupils without disabilities aged 6–17 years, and only activities performed by more than 10% of the sample were to be included in a proposed Swedish version of the CAPE. Descriptive analysis, an independent samples t-test, and a paired samples t-test with standardized mean scores were used to analyse the results (Tables 2 and 3).

Study II

A cross sectional, descriptive, and comparative design was used to investigate the patterns of participation in children with and without disabilities regarding diversity, intensity, and enjoyment in five leisure activity types. In total, 337 children without disabilities from Study I and 55 children with disabilities aged 6-17 years completed the Swedish version of the CAPE questionnaire. Analyses performed were a t-test for independent samples, linear multiple regression analyses, and a Chi-square test for independence (Tables 2 and 3).

Study III

A cross-sectional comparative and descriptive design was used to explore whether patterns of participation in leisure activities differed for children with and without disabilities living in Norway, Sweden, and the Netherlands. The Swedish study population consisted of same children from Studies I and II. The sample population from Norway consisted of 104 children without disabilities and 158 children with disabilities and the Dutch study population consisted of 158 children without disabilities and 74 children with disabilities. All children were in the age range of 6–18 years. The children responded to the original version of the CAPE concerning diversity, intensity, and enjoyment of participation in five different activity types and the results were analysed. The analyses used were one-way between-groups analysis of variance tests (ANOVA), hierarchical multiple regression analysis, and Chi-squared tests (Tables 2 and 3).

Study IV

A pilot intervention study with a client-centred approach and a single-subject AB design was performed to increase children's participation in leisure activities. Two boys with neuropsychiatric diagnosis aged 12 and 14 years old were included. Baseline measures (performed during 2 weeks) consisted of the CAPE and the PAC, GAS to formulate levels of goal achievement, and the perceived ability performance scale of

the COPM and finally estimations of self-efficacy. Thereafter repeated baseline measures were conducted during the intervention (Figure 2 and Table 2 and 3).

The intervention had a client-centred approach and was carried out over 8 weeks by three therapists at the rehabilitation centre. The intervention took place in the child's everyday environment and at the habilitation centre and focused on the child's individual leisure activity goals. The children worked with different individual strategies to attain the goal, together with the therapist, the parent or alone. The implemented treatment strategies, the duration and frequency were recorded by the therapist and by the child using log books. Once a week, the child participated in group meetings to continuously evaluate the implemented strategies and to identify solutions for goal attainment. The meetings were also used for discussing and exercising topics such as "How should a good friend be?", "How can I get in contact with a peer?", "What can I do together with a peer?"At the end of week 10, all assessments were repeated to evaluate the intervention outcome. The families and the therapists answered questions about the intervention's efficacy and the therapists also evaluated the clinical utility of the CAPE/PAC.

Table 2 Summary of study aims, design, number of participants, and methods included in the four studies.

Study	Aim	Design	Participants	Methods
I	To culturally validate the CAPE for Swedish Children	Cross cultural validation in a cross sectional study	*n* = 51, children without disabilities (group interviews) *n* = 337, children without disabilities (questionnaire) *n* = 15, children with disabilities (group interviews) *n* = 8, parents to children without disabilities *n* = 4, parents to children with disabilities	Translation and back-translation, group interviews, item revision and adaptation, field test of adaptedquestionnaire, and psychometric test.
II	To describe and compare patterns of participation in Swedish children with and without disabilities	Cross sectional study with descriptive and comparative design	*n* = 337, children without disabilities from Study I *n* = 55, children with disabilities	A survey using the Swedish culturally adapted version of the CAPE.
III	To investigate if participation in leisure activities varies for children with and without disabilities living in Norway, Sweden and the Netherlands	Cross sectional study with descriptive and comparative design	*n* = 337, Swedish children without disabilities *n* = 55, Swedish children with disabilities (the same children, from Studies I and II) *n* = 104, Norwegian children without disabilities *n* = 158, Dutch children without disabilities *n* = 149, Norwegian children with disabilities *n* = 74, Dutch children with disabilities	A survey using the CAPE in three countries.
IV	To implement, describe, and investigate the feasibility of an intervention model and the CAPE/PAC	A pilot intervention study with a single subject AB design	*n* = 2, children with disabilities	Client-centred intervention.

3.3 PARTICIPANTS, RECRUITMENT PROCESS AND DATA COLLECTION

3.3.1 Participants: Study I

In Study I, a sample of 51 children without disabilities participated in nine semi-structured group interviews of 4–6 children in each group. The groups were divided into three age categories: 6–8 years, 9–11 years, and 12–15 years. Approximately half of the children were females. Group interviews with eight parents of children aged 6–15 years were also performed. Three semi-structured group interviews were carried out with 4–6 children with physical disabilities aged 6–17 years. Finally, a semi-structured group interview was conducted with four parents to children with disabilities. Cerebral palsy was the most common diagnosis among the children.
Additionally, 337 children without disabilities (164 males, 173 females; aged 12 years (6–17) SD 2.0) responded to the Swedish-adapted version of the CAPE.

3.3.2 Data collection: Study I

The semi-structured group interviews of children without disabilities took place at four different schools. The schools represented various regions of Sweden, which may influence the variety of leisure activities: coast/midland, snowy landscape, rural areas, and urban areas. The semi-structured group interview with parents was also carried out at one of the schools. The semi-structured group interviews with children with disabilities and the semi-structured group interview with parents to children with disabilities were accomplished at the rehabilitation centre in Uppsala and at a mainstream school in Uppsala. The interviews were led by one of the researchers who asked questions about what kinds of indoor and outdoor leisure activities children could participate in during different seasons. Lists of leisure activities were generated and these leisure activities were individually matched to the original leisure activities in the CAPE by the three researchers. Discussions with the authors of the CAPE were held when it was unclear how to categorize the activities within the CAPE items.

In total, 16 new leisure activities were listed and added to a modified trial version of the CAPE. These leisure activities could either not be fit into the original version of the CAPE or needed to be clarified. The modified trial version of the CAPE, including the 55 original leisure activities plus the 16 new potential activities, was tested on 337 children without disabilities. The children were recruited from the same four schools mentioned above and from two other schools representing a socioeconomically privileged area and a school at which nearly 60% of the pupils are immigrants. The children in the age range of 8–17 years completed the CAPE questionnaire in the classroom. The youngest children (aged 6–7 years) completed the CAPE questionnaire at home in case they needed the assistance of a parent

3.3.3 Participants: Study II

Study II consisted of the same 337 children without disabilities recruited to participate in Study I, and 55 children with disabilities. Only children without, or with mild, intellectual retardation were included. Fifty-five children (29 males, and 26 females age: 6-17, M = 11 years, SD 2,7) with disabilities related to the central nervous system and/or musculoskeletal or neuromuscular problems participated in the study.

3.3.4 Data collection: Study II

The data collection for children without disabilities was conducted in their schools and for the youngest children at home. The occupational therapists working at 13 different paediatric rehabilitation centres invited 110 children from their current case load to answer the Swedish version of the CAPE. The rehabilitation centres were situated in rural and urban areas in the north, east, and west of Central Sweden and represented different socioeconomic districts. All the children with disabilities responded to the Swedish version of the CAPE at home.

3.3.5 Participants: Study III

In study III the Swedish sample consisted of the same children with and without disabilities as in study II. The Norwegian sample consisted of 104 children without disabilities aged 7 to 14 years (M = 11.1, SD 2.5), and 149 children with physical disabilities aged 8 to 18 years (M = 11.9, SD 2.6). From the Netherlands, a convenience sample of 158 children without disabilities aged 6 to 18 years (M = 11.0, SD 3.1) and 74 children with physical disabilities aged 6 to 18 years (M = 12.0, SD 3.4) participated.

3.3.6 Data collection: Study III

The data collection of Swedish children with and without disabilities was conducted as described in Studies I and II. The Norwegian children without disabilities were recruited from five schools situated in urban and rural areas of southeastern Norway with different socioeconomic districts. The CAPE questionnaire was answered in the classroom with one of the researchers and the teacher available to answer questions. A physiotherapist delivered the CAPE to children with physical disabilities during their rehabilitation period at Beitostølen Healthsport Center (BHC). The children answered the CAPE questionnaire together with their parents, and a physiotherapist was available to answer questions. The Dutch children without disabilities were recruited from schools in different regions of the Netherlands. The CAPE was answered by children younger than 12 years in a one-on-one session with a research assistant and the older children completed the CAPE in the classroom with a research assistant available for assistance. The Dutch children with disabilities were eligible if they were able to complete the CAPE with or without assistance and were recruited from two special schools and from a rehabilitation centre. The CAPE questionnaire was completed in school or at home in a one-on-one session together with a research assistant.

3.3.7 Participants: Study IV

In the pilot intervention study, a convenience sample of two children with neuropsychiatric diagnosis, Asperger's disorder, and Attention Deficit Hyperactive Disorder, ADHD aged 12 and14 years were recruited to participate. Inclusion criteria were no, or only mild, intellectual impairment, and a supportive family or social network.

3.3.8 Data Collection: Study IV

The rehabilitation centre in Uppsala was invited to participate. The therapists, an occupational therapist, a recreation instructor, and a physiotherapist (researcher) recruited children with neuropsychiatric diagnosis to participate in the study. For descriptive and goal setting purposes, the children responded to the CAPE and the PAC. The GAS was used to formulate levels of goal achievement. Baseline measures consisted of the perceived performance ability scale of the COPM and estimations of self-efficacy, and were conducted until they showed stability. These data were also collected during the intervention. At the end of the intervention, all assessments were repeated to evaluate the intervention outcome. An independent therapist evaluated the GAS scales. The two children and their parents answered questions about the intervention's efficacy and so did the occupational therapist and the the recreation instructor. The therapists also answered questions about the clinical utility of the CAPE/PAC.

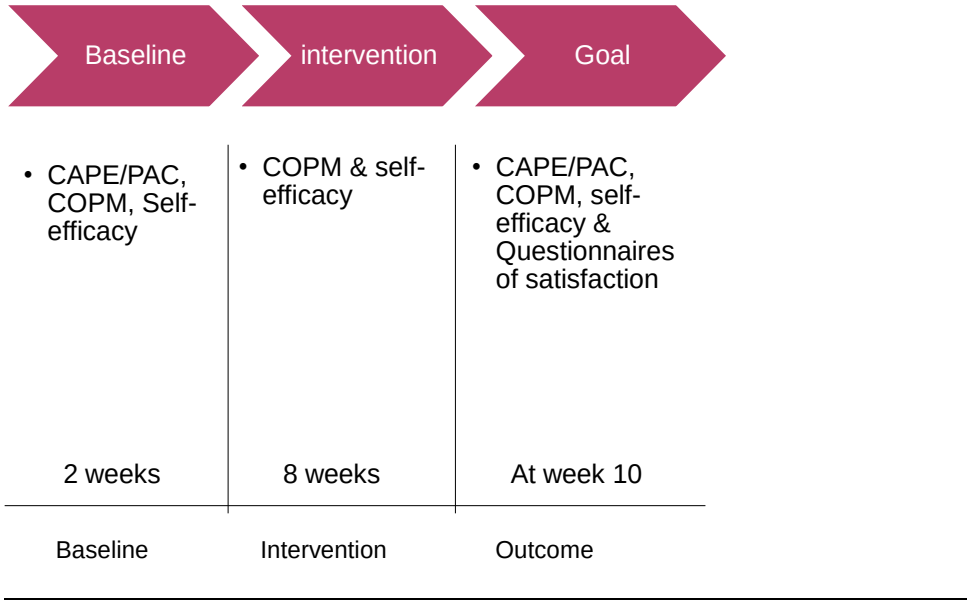

Figure 2 The flow diagram of the intervention

3.4 ASSESSMENT INSTRUMENTS

3.4.1 The Children's Assessment of Participation and Enjoyment/ Preferences for Activities of Children (CAPE/PAC)

The, CAPE/PAC is a self-reported assessment appropriate for children with and without disabilities between 6 to 21 years of age and was developed in Canada (9, 160). The CAPE is a 55-item assessment with five dimensions of participation: (1) Diversity (the number of activities participated in, answered 'Yes' or 'No'), (2) Intensity (the frequency of participation measured as a function of the number of possible activities within a category, answered on a scale ranging from 1 – 'once in the past four months' to 7 – 'once a day'), (3) With whom (with whom the child performs the activity, answered on a 5-point scale), (4) Where (where the activity takes place, answered on a 6-point scale), and (5) Enjoyment (how much the child enjoys the activity, answered on a scale ranging from 1 – 'not at all' to 5 – 'love it'). These five dimensions can provide scores on three different levels: (I) overall participation score, (II) domain scores of participation in 15 formal and 40 informal activities, and (III) scores reflecting participation in five types of activities: Recreational activities, active physical activities, social activities, skill-based activities, and self improvement/educational activities (9, 160). (See description of scores in Study I, Table 1, p. 430)

The PAC is a parallel assessment of the child's preferences for activities and includes questions about how much the child would like to do an activity. The child estimates his or her preferences for the same 55 leisure items as in the CAPE by answering: (1) I would not like to do at all, (2) I would sort of like to do, and (3) I would really like to do.

The CAPE/PAC covers all of the ICF/ICF-CY's life areas, except those from chapter 5, Self care (15, 22, 69), and comprises behaviour aspects (diversity and intensity of participation), contextual or environmental aspects (where and with whom activities take place), and affective aspects (enjoyment and preferences of activities) (9, 160).

Several studies have provided indications of the reliability and validity of the CAPE outcomes, including studies from Sweden and the Netherlands [28, 43-47]. The content validity of the CAPE/PAC was established by literature review, expert review, and pilot testing of content items. Factor analyses of the PAC data were performed twice to formulate the scoring structure and showed that 35 items (74%) loaded twice in the same five different factors: Recreational activities, active physical activities, social activities, skill-based activities, and self improvement activities (9) . The remaining activity items were carefully studied and placed into the most suitable activity type.
The stability of the CAPE was evaluated by test-retest reliability (9, 36) indicating a moderate intraclass correlation ranging from 0.64–0.86 for diversity, intensity, and enjoyment scores for the overall participation and for the domain scores (9, 36). The internal consistency illustrated by Cronbach's coefficient alpha ranged from 0.67–0.77 for the PAC scores of five activity types and from 0.30–0.62 for the CAPE scores of the five activity types (9). The CAPE has also reported sufficient inter-interviewer reliability, and the intraclass correlation coefficient for the intensity scores ranged from 0.66–0.83 (161).

3.4.2 Goal Attainment Scaling (GAS)

In rehabilitation and health services for children with special needs, it is important that the child and the family are involved in establishing for themselves relevant goals in the planning of rehabilitation and evaluation of outcomes (151, 162). To evaluate quality in progress and outcomes of rehabilitation based on individualized approaches, a standardized measure where all individuals are assessed along similar dimensions using the same measures and having similar goals is not sufficient. Instead sensitive, individualized approaches are needed to measure individual changes (153, 155). The GAS, first introduced by Kiresuk and Sherman in 1968 to evaluate mental health services, is a method of measuring individual progress towards individual goals (153, 162, 163). The GAS is a five-point scale, with -2 representing the current level of performance at the time of goal setting (baseline). -1 is given if the child's progress is less than expected and 0 indicates the expected level of goal performance. If the child achieves more than expected, a level of +1 or best expected outcome ;+2 is given (151, 152, 163, 164).When using individual multiple goal scales, the scores can be converted into an average summary T-score. A mean T- score of 50 (SD 10) will indicate attained goals. The T-score provides a method for quantifying change over time and across groups of individuals. The relative importance or difficulty of each goal can also be weighted so that the T-score reflects the emphasis placed on each goal during treatment (153, 162, 164, 165).

To be able to use the GAS effectively, it is important that the rater has a sufficient level of clinical experience so that they can set realistic goals, and have had orientation and specific training in using the GAS (151, 152, 164). Further the goal should be specific, measurable, acceptable, relevant, and time-related (SMART) (151-154).

The GAS has provided evidence of high content validity, and Palisano showed that physical therapists can select important goals for function and motor development and that the goals are scaled to measure clinically crucial changes that infants with motor delay are capable of attaining (166). The concurrent validity was low when comparing the GAS T-scores with the Peabody gross motor age-equivalent change scores (r= 0.25, p= 0.14) (166). Cusick et al. did not find any correlations between the COPM and the GAS (162). This means that the GAS individualized goal attainment scale captures aspects of improvements, probably detailed aspects that are not seized upon by the more comprehensive Peabody and COPM outcomes. The inter-rater reliability was found to be high, with a Kappa coefficient of 0.82- 0.89 (153, 166, 167) and the sensitivity of the GAS, referring to its ability to detect change, was also observed to be high (132, 153, 155, 164, 168).

3.4.3 Canadian Occupational Performance Measure (COPM)

The COPM is based on a client-centred approach and is an individualized outcome measure of changes in a client's performance and satisfaction in occupation over time (169) . In a semi-structured interview, the client identifies problem areas within self-care (activities of daily living), productivity (education and work), and leisure (play, recreation, and social participation) (169). After problems are identified the client rates his or her ability to perform these activities and his or her satisfaction with the performance using the same scale 1-10 (169). Higher ratings indicate better performance and more satisfaction. The COPM has been widely used in children with disabilities, adults with neurological disabilities, stroke patients, patients with hip

fractures and traumatic brain injuries, and patients with chronic obstructive pulmonary diseases (132, 156, 170, 171). Many studies have described the COPM as being effective in setting appropriate goals, engaging clients in the therapeutic process and in assessing a wide range of client problems (132, 156, 170, 172). The COPM has provided evidence of test-retest reliability with a correlation coefficient of 0.89 for performance scores (p=<0.001) and 0.88 for satisfaction scores (p=<0.001) when being used with stroke patients (171). Verkerk et al showed that 80% of the problems identified by parents to children with disabilities were re-identified as problems a second time after one week (156). In the review of the COPM by Carswell et al. reports of evidence for content, concurrent validity and responsiveness were demonstrated (170).

3.4.4 Self-efficacy for goal attainment

Self-efficacy is a judgment about one's ability to successfully perform a task at a given level. Personal goal setting is influenced by self-appraisal of capabilities. "The stronger the perceived self-efficacy, the higher goal challenges people set for themselves and the firmer is their commitment to them" (p.118) (101). Because no suitable measure of self-efficacy for children was found, the children estimated their self-efficacy in coping with the goal activity and finally attaining the goals on a simple rating scale with five statements: 1 (I am not able to attain the goal), 2 (I am limited in my ability to attain the goal), 3 (I am able to attain the goal), 4 (I am quite able to attain the goal), and 5 (I am without doubt very able to attain the goal).

3.4.5 Feasibility ratings

Questionnaires to children and families
To investigate the children's and parents' opinions, satisfaction and experiences of the intervention model, two questionnaires were designed including three open questions and nine statements of the efficacy of the intervention i.e." I have/my child has attained the goal, I have/my child has obtained a higher self-efficacy, I have/my child has enjoyed in attending the group meetings" ranged from (1) I do not agree to (5) I totally agree.

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Questionnaire to the therapists
To analyse the clinical feasibility and utility of the CAPE/PAC in measuring participation in leisure activities and to identify the preferred leisure activities of children, the therapists utilized a visual analog scale from 0–10 where 0 = 'CAPE/PAC is not at all useful' to 10 = 'CAPE/PAC is very useful'. The questionnaire also included 11 questions about the efficacy of using the GAS, COPM, and the self-efficacy questions, the logbooks and group meetings, the therapist's compliance in the intervention, and the efficacy of the education in the GAS, the CAPE/PAC, and in

factors influencing participation. The therapists used visual analog scales from 0–10 to answer these questions where 0 = ‘not at all useful’ and 10 = ‘very useful’.

3.5 STATISTICS

The statistical methods and analysis tools in each study are summarized in Table 3 and will be presented in detail in the sections below.

Table 3 Summary of statistical methods and analysis tools used in the individual studies.

Methods and tools for statistic analysis	Study I	Study II	Study III	Study IV
Descriptive statistics	x	x	x	x
Cronbach’s alpha statistics	x			
Independent samples t-test	x	x		
Paired samples t-test with standardized mean scores	x			
One-way analysis of variance (ANOVA)			x	
Linear multiple regression		x		
Hierarchical multiple regression analysis			x	
Chi- squared analyses		x	x	
Visual inspection and comparison of patterns in baseline data and in intervention to determine the outcome				x

3.5.1 Study I: data analysis and statistics

The research group decided to keep the original format of 55 activity items and decided that only activities performed by more than 10% of the sample were applicable for Swedish children and, therefore, should to be included in the Swedish version of the CAPE. An independent samples t-test was used to compare the mean scores of how easy or difficult the children estimated the CAPE questionnaire was to complete. A paired samples t-test with standardized mean scores was used to analyse differences between the children’s responses on the activity diversity scores of the two versions of the CAPE, the original version and the proposed Swedish version. A standardization of the mean scores was necessary to be able to compare scales with different numbers of items and was performed on the 0–100 scale method (100 divided by the number of activities on the specific activity scale of the two versions multiplied by the number of activities performed).

Cronbach’s alpha statistics were used to evaluate the internal consistency between the two versions of the scales. Internal consistency refers to the average correlation between the items in a scale, and whether the scale items assess a single construct (88, 91-93, 157). Values range from 0 to 1, with a higher value indicating a higher

correlation. When coefficient alpha is used, the recommendation is that the level of reliability should be at least 0.70–0.80 (92, 157). The level of statistical significance was set to 0.05.

3.5.2 Study II: data analysis and statistics

To compare the patterns of participation in children with and without disabilities in regards to the sum of diversity scores, the mean of intensity scores, and the mean of enjoyment scores in five activity types, a t-test for independent samples was calculated. An independent samples t-test was also used to compare the ages of children with and without disabilities. The level of statistical significance was set to 0.05. To analyse if differences existed between children with and without disabilities regarding gender and the educational level of the mothers, a Chi-square test for independence (with Yates continuity correction) was conducted. Based on the parents' occupations, the mother's educational level was aggregated into "university-level education" or "less than university education".

To explore how well the independent variables age, gender, mother's level of education, and occurrence of disability could explain the variance in diversity, intensity, and enjoyment in the five activity types, a linear multiple regression analysis was conducted. Linear multiple regression analyses were also used to investigate which of the independent variables most significantly contributed to participation in the five activity types. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity.

3.5.3 Study III: data analysis and statistics

The intensity scores were merged into three new categories: seldom/never, regularly, and often. For each participant, the overall percentage of activities done seldom/never, regularly, and often were calculated and divided by the total number of activities in each activity scale and the ratio was multiplied by 100. The use of percentages instead of absolute numbers allowed comparison of the five activity types with different numbers of items. To analyse the impact of country of residence on the percentage of activities done: seldom/never, regularly and often, and on diversity, for each of the five activity types, one-way between-groups analysis of variance tests (ANOVA) were calculated. *Post-hoc* comparisons using the Tukey test were performed when a significant difference between groups was present. The one-way between-groups ANOVA was also used to investigate if there were significant differences between the three countries regarding age. To analyse if differences existed between the countries concerning gender, the educational level of mothers, and the geographical area of living, a Chi-squared analysis was calculated.

Hierarchical multiple regression analysis tests were used to assess the ability of the three independent environmental variables, educational level, geographical living area, and country of residence, to predict the outcome scores of diversity and intensity in the five activity patterns of participation after controlling for the influence of age and gender. Age and gender were entered in Step 1, while educational level, geographic area, and country of residence with dummy variables for each country were entered in Step 2. Analyses were performed to ensure no violation of the assumptions of normality, linearity, multicollinearity and homoscedasticity. The alpha level for all analyses was set to $p = 0.05$.

3.5.4 Study IV: data analysis and statistics

The repeated measures between baseline and the intervention were plotted. The median values from the estimations of self-efficacy and performance ability were calculated and compared across baseline and intervention (158). By visual analysis, it was possible to compare the level, variability, trend, and slope in baseline data to those in the intervention data and it was determined if the patterns of results supported the conclusion that the interventions had the hypothesized effect (173). The level of change in magnitude for performance ability and self-efficacy estimations between baseline and intervention demonstrated if an abrupt increase or decrease occurred. The instant and magnitude of change in levels will indicate the strength of the intervention (158, 174). The variability was analysed by inspecting the degree of fluctuation of data points because a high fluctuation of data complicates and undermines the interpretation of a possible intervention effect (158, 173). By visual inspection, the changes of the data pattern's direction and the steepness of data paths across baseline and intervention were indicative of the trend and slope of the outcome variables.

4 RESULTS

4.1.1 Study I

The original CAPE format of 55 items was decided to be kept. From the response rates gained for all 71 activity items, only items performed by more than 10% of the Swedish children were included in the Swedish version of the CAPE. Three of the original CAPE activities did not meet this criterion and were excluded: "Taking art lessons" (8%), "Participating in school clubs" (10%), and "Doing volunteer work" (8%). Three of the 16 new trial items met the criteria and were added to the Swedish version: "Going to a café/restaurant" (78%), "Outdoor play" (59%) and "Doing individual sport in a club" (22%). The remaining 10 trial items were recommended to be added as new examples of the original activities in the CAPE questionnaire and to appendix A of the CAPE manual (see the proposed Swedish version of the CAPE in Study I, Table II, p. 432). The standardized mean outcomes of the Swedish diversity scores were significantly higher for all activity types than the standardized mean outcome scores of the original version (see comparisons of standardized mean scores in Study I, Table IV, p 435). The internal consistency for the items of the five activity types in the Swedish version of CAPE were calculated to be 0.58–0.81. The CAPE questionnaire was found to be easy or rather easy to complete by 94% of the pupils and no significant differences in the ratings of easiness were found between regions or schools.

In conclusion, it was important that the Swedish version of the CAPE included items that were appropriate for Swedish children and still applicable for international comparisons. After minor adjustment, some items and their content became clearer to the Swedish children. The fact that activities in the Swedish version were more applicable resulted in a higher standardized mean diversity score for the Swedish version than that of the original version of the CAPE, which indicated a more culturally valid version.

4.1.2 Study II

Children with disabilities participated in a significantly higher number of recreational, social, skill-based, and self-improvement activities compared to children without disabilities, but with less intensity in social, physical, skill-based, and self-improvement activities than children without disabilities.
In regards to enjoyment, children with disabilities had significantly higher scores of enjoyment in recreational and self-improvement activities than children without disabilities

The results illustrated that the independent variables age, gender, the mother's educational level, and occurrence of disability could explain 2.9% to 36% of the variance in *diversity* outcome of five activity types. Results in detail are presented in Study II, table 4 page 15. In conclusion, younger children, girls, children with disabilities and children who have a mother with a higher educational level participated in the highest number of activities.

In regards to the *intensity* of participation in the five activity types, the independent variables could explain 2.9–16.2% of the variance. Results in detail are presented in Study II, table 5 page 17. In summary, children without disabilities participated with a higher intensity in social, physical, and self-improvement activities than children with disabilities. Adolescents participated more frequently in social activities, whereas

younger children performed recreational activities with a higher intensity and, finally, boys participated with a higher intensity in physical activities

The results relating to the *enjoyment* of participation in the five activity types demonstrated that the independent variables could explain between 5.2% and 16.6% of the variance in enjoyment. Results in detail are presented in Study II, table 6 page 19.
Younger children tended to enjoy recreation activities the most, and boys and children who had a mother with university education had higher enjoyment in physical activities.

In conclusion, the children with disabilities participated in a higher number of leisure activities but with less intensity compared to the children without disabilities. It is probably the combined impact of several personal and environmental factors rather than single factors such as impairment, parental education, age, or gender that influence the child's pattern of participation in leisure activities. Longitudinal studies of participation in leisure activities are essential to increase the knowledge of changes over time in children's preferences for activities, and research designs based on individual and qualitative methodologies are needed to understand the child's perspective of the concept of participation in leisure activities.

4.1.3 Study III

Differences between countries in children's diversity outcome
Results in detail are described in Tables 3 and 4 in Study III p.374-5. Concerning the diversity of participation, the Norwegian and Swedish children with disabilities performed a significantly higher number of activities than the children from the Netherlands in all activity types, except for recreational activities.
The same pattern could be seen for children without disabilities.

Differences between countries in children's intensity outcome
Results in detail are described in Tables 3 and 4 in Study III p.374-5. In general, the Dutch children with disabilities tended to participate with a lower intensity in all activity types compared to the Swedish and Norwegian children.
For children without disabilities there were mainly differences in the intensity outcome concerning social and physical activities where the Scandinavian children participated with a higher intensity compared to the Dutch children.

Personal and environmental variables predicting children's diversity outcome
For children with disabilities, the environmental variables could explain between 12.0% and 26.7% of the variance in the diversity outcome of the five activity types after controlling for the personal variables.
For children without disabilities, the environmental variables explained less of the variance, 8.3–12.7%, of the diversity outcome scores of the five activity types.
Gender was the main predictor followed by country of residence for children with and without disabilities. Results in detail are presented in Table 5 in Study III on p. 376 and in the appendix on p. 381.

Personal and environmental variables predicting children's intensity outcome
For children with disabilities, the results showed that the personal and environmental independent variables could explain 8.2% to 26.7% of the variance of intensity in the five activity types. The country of residence was the main predictor in 9 of 15 (60%)

activity types, and was the strongest predictor in all activities done on a regular basis and in social and self-improvement intensity outcome scores. Results in detail are presented in Table 6 in Study III on p. 377 and in the appendix p. 382-385.
For children without disabilities, the independent variables could predict between 3.2% and 14.9 % of the variance in intensity scores in the five activity types. Results in detail are presented in Table 6 in Study III on p. 377 and in the appendix p.382-385. Gender was the strongest predictor in 9 of 15 (60%) intensity activity types, and the main predictor in physical, skill-based and self-improvement activities. Country of residence was the main predictor in recreational and social activities.

In conclusion, the Scandinavian children with disabilities participated with a higher diversity and intensity in leisure activities than the Dutch children. For children without disabilities, the main differences were seen in social and physical activities. The environmental factor country of residence had a considerable influence on the patterns of participation. This was especially the case for children with disabilities. For children without disabilities the, personal variable gender was the main predictor in diversity and intensity outcome scores. The difference between the Scandinavian countries and the Netherlands may reflect differences in the education systems, differences in national policy of transportation and legislation directed at assistive technology, equality of information, support and welfare services, or accessibility. Further analysis of the physical accessibility, community programs, and the causes of national heterogeneity are essential to provide evidence for changes to national legislation and policies that promote participation for children with disabilities.

4.1.4 Study IV

After the intervention the two participants had succeeded in attaining their goals as specified by the GAS by passing the 0-level, and even achieving +2 on one goal and +1 on the other two goals. The results of the repeated measures of the performance ability and the self-efficacy were plotted and visual inspection indicated a pattern of level, slope and trend, increased from the baseline ratings during the intervention phase for goals 1 and 2, a judgment shared by all raters. For goal 3, the ratings were highly variable.

The results from the questionnaires completed by the participants, parents, and therapists indicated that, in their opinion, the intervention had been effective in improving the child's participation in leisure activities and that the CAPE and PAC were feasible to use in the clinic.

In conclusion, the implemented intervention with a client-centred approach facilitated children with neuropsychiatric diagnoses to decide on and attain leisure activity goals that were important to them. The CAPE and PAC were effective self-reported assessments in this work. It is essential to carefully analyse personal and environmental barriers and facilitators for children's participation because this will provide the therapist with ideas of which strategies should be implemented for goal attainment.

5 DISCUSSION

5.1 ASSESSING THE CONSTRUCT OF PARTICIPATION ACROSS NATIONS

The results from this thesis indicate that the child's participation in terms of diversity, enjoyment and intensity of attendance in leisure activities is a product of a continual process between the child and several environmental factors in the child's bio-ecological systems. This highlights the need for a careful validation of conceptual and item equivalence of the CAPE/PAC for Swedish children.

5.1.1 Psychometric vs. clinimetric

When deciding what activities were to be included in the Swedish version of the CAPE/PAC, measure equivalence was investigated, i.e., examining whether the psychometric aspect of validity and reliability properties produced interpretable results of the original and the Swedish versions of the CAPE/PAC (86, 89). A common psychometric method to evaluate *criterion validity* is to examine internal consistency, the correlation between items and scales. The homogeneity of items is necessary for reliability because all items in a measure are supposed to exploit the same construct and, therefore, would be correlated with one other (92, 93). The internal consistency was calculated for the items in the five activity types, recreational, physical, social, skill-based, and self-improvement, of the CAPE by Cronbach's coefficient alpha and showed low to moderate correlations of 0.58–0.81. The lowest correlations were found for skill-based and self-improvement activities and are probably due to that these activity types consists of a range of unrelated different activities. For example, skill-based activities are representing both physical and cultural activities and outcomes of e.g. high diversity or frequency in one of these domains does not necessarily imply high intensity or frequency for the other. Cronbach's alpha is recommended to be at least 0.80 depending on the number of items and the sample size (86). Scales including a higher number of items and a larger sample size, will lead to a high Cronbach's alpha, and Cortina (1993) has claimed that Cronbach's coefficient alpha is ineffective for scales with more than 40 items because a higher number of items automatically lead to a higher internal consistency (175). The question is however, if a multidimensional construct, like participation in leisure activities, can be validated using psychometric methods. Participation may instead be observable through a number of indicators, all of which alone are imperfect measures of the construct but which together provide a more valid operationalization (52, 57)

Items involved in a measure of the construct of participation are likely to have low inter-correlations. According to psychometric rules, items that might reduce the clinical validity of a measure should be removed. When creating a measure of participation, it is feasible to develop a scale including items with low or even negative correlations as long as the items all together map the multidimensional construct (52, 57, 92). For instance, it is difficult to claim that just because a child likes to hang out with friends that he or she also likes to make food, both referred as social items in the CAPE/PAC. Another reason for not using Cronbach's coefficient alpha is that strongly intercorrelated items are highly redundant; if one item is included in the scale the other item will not contribute with new information, so to say you can write the same question in many ways (91). Modern test methodologies, such as the Rasch

measurement model, also would not be applicable because no hierarchy can be assumed between the items measuring the construct of participation. It is, indeed, impossible to give a higher value or difficulty level to one activity than to another (57). Response Theory measures the most commonly performed item as the easiest. This might mean with respect to leisure activities for children with disabilities that horseback riding is regarded as easier than playing a musical instrument, which, of course, is not true for everyone. Participation profiles among individuals depend on their individual skills and previous experiences as well as the fact that children tend to seek out niches that are congruent with their talents and interests. This makes it irrelevant to hierarchically rank different activities according to degree of difficulty for comparing patterns of participation between children (84, 102).

When measuring participation in leisure activities, it is essential that the objective (frequency and diversity of performance) and subjective (enjoyment and preferences for activities) dimensions of the construct are captured, thus the construct cannot be captured in a single measurement scale (52, 78). Instead, many different subscales, all including important causal indicators of attributes influencing the construct, are needed when assessing the construct. When using a clinimetric approach to decide which items to be included in an assessment, it is the judgments of the clinicians and patients that are essential to identifying different attributes of the construct, often heterogeneous in their characteristics and reflecting different aspects of the construct, that are important to include in the assessment (95, 96, 176). Further, the scale should be quick and easy to use and the items should be selected by face validity and should be meaningful and relevant to the intended population (84, 102).The Apgar score is found to be an excellent example of a scale developed with a clinimetric approach (96). The Apgar score is a quick and simple method consisting of five different dimensions, Appearance, Pulse, Grimace, Activity, and Respiration to be used to assess the health of newborn children on a scale from 0 to 10 (176, 177).

Marx et al. have investigated whether clinimetric and psychometric strategies provid comparable scales of an upper extremity disability measurement. Their results showed that the two strategies led to scales that provided similar overall scores, but with a clinimetric strategy a greater number of items were selected to be more relevant to the patient, such as symptoms and psychological items, and the psychometric method selected more physical disability items (97).

The culture validation of the CAPE/PAC took a clinimetric approach with group interviews and clinical tests of the modified version. A careful inventory by face validity of item relevance and a cutoff point of activities performed by less than 10% were set to identify important activities to be included in the Swedish version of the CAPE. With minor adjustment by excluding three activities, including three new activities, and adding some examples, we developed a valid Swedish version of the CAPE. In Study IV, when using the Swedish version of the CAPE/PAC in an intervention with the aim to enhance children's participation, the therapists found the modified version of the CAPE to be an efficient survey of the child's patterns of participation and to identify goals.

5.2 FACTORS RELATED TO PARTICIPATION IN LEISURE ACTIVITIES IN CHILDREN WITH AND WITHOUT DISABILITIES, NATIONALLY AND INTERNATIONALLY

5.2.1 Generic environmental factors influence participation in leisure activities

The literature has identified several different environmental factors influencing a child's patterns of participation that all need to be considered when using the CAPE/PAC in a new culture (5, 7, 12, 58, 80, 178). Consequently, it was important to study the conceptual equivalence of participation and item equivalence of the CAPE/PAC for the Swedish children. The results indicated that minor cultural differences existed between the Swedish and Canadian cultures. Swedish children tend to spend more time in informal activities, like outdoor play, and less time in activities such as volunteer work and school clubs compared to the Canadian children. The fact that the Swedish children with and without disabilities spent more time in informal social activities was also confirmed in Study III when comparing differences between Sweden, Norway and the Netherlands. Swedish children with and without disabilities were shown to have a higher diversity and intensity in social activities compared to the Dutch children. Therefore, two new items, 'outdoor play' and 'going to a café or restaurant', were added to the Swedish version of the CAPE that capture social activities not included in the original version but that are frequently performed by Swedish children.

According to the bio-ecological model, we know that environmental factors on the macro systems level, such as different cultural traditions, differences in school and health services, and different laws and regulations will indirectly influence the child's patterns of participation. The dissimilarities between the countries in this thesis may be explained by different school systems. Swedish children have more unscheduled out of school time, hence more time to spend in leisure, compared to the Dutch children. Dutch children in primary school (4–12 years of age) spend 7520 hours in school in total for 8 years and children in secondary school (12–16 years old) spend 1040 hours in school. This is compared to Swedish children (7–15 years old) who are only obligated to 6665 hours in total in school for 9 years (179, 180). Additionally, in the Netherlands 62% of the children with special educational needs attend segregated schools, compared to less than 4% in Sweden (SNE Country data, 2010)(179, 180). There is evidence to suggest that children with disabilities who are included in regular classes have more opportunities to gain the same social participation and theoretical knowledge as children without disabilities. This may explain the differences in participation level in children with disabilities (63, 83, 107).

Other explanations for the differences in the participation patterns might be that Sweden has public after-school recreational centres that are attended daily by both children with and without disabilities providing them with opportunities to participate in diverse leisure activities (106, 181). Instead of having public after-school recreational centres, Canadian children attend school clubs directed towards specific activities such as sports, science, or art. Because Swedish children do not recognize this phenomenon, and it does not seems to be relevant to Swedish children, the item 'School clubs' was recommended to be deleted.

Moreover, regarding the items equivalence, the cultural validation also revealed that Swedish children could not relate to the item 'Voluntary work'. This involves a concept

not really used in Swedish society, especially not among children, and charitable activities are rarely performed among Swedish children. A plausible explanation for this is that the Swedish social security system covers the costs for education and public medical service and in Sweden government-administered aid to developing countries is proportionally among the highest in the world (30 263 823 SEK or 1% of BNP) (182). In Canada it might be more common to do volunteer work such as helping elderly people, running errands for the teacher, raising money for charity, etc. This cultural dissimilarity resulted in exclusion of the item 'Voluntary work' in the Swedish version. In addition, cultural changes caused by the development of society and technological inventions will also influence children's participation in leisure activities. Because it is almost a decade since the CAPE was published, some of the items needed a more modern expression, e.g., 'talking on the phone' was suggested to be updated to include 'text messaging' in the Swedish version.

The differences in children's participation between countries have also been demonstrated in a cross-sectional European study of children aged 8–12 years with cerebral palsy. In this study, one third of the variance could be ascribed to variation between countries (58). The authors suggested that differences between countries might be explained by dissimilarities in social security, care and health services, education, access to assistive technology, transportation, and information (58). The cultural differences between countries underscore the importance of not only translating a measure when using it in a new cultural context, but also of studying the conceptual equivalence of participation and the item's relevance for the new population. Further, the majority of the dissimilarities in the children's participation among European countries were influenced by other factors, such as walking ability, pain, and intellectual and communication skills, that need to be considered when investigating the child's patterns of participation.

Another environmental factor that has been reported to influence the child's participation in leisure activities is the population density of the child's living area (109-111). The results from Study III indicated that it was only in organized formal activities like physical and skill-based activities that the living area could explain variance in diversity and intensity of participation. In rural areas, children with disabilities participated with less intensity in physical activities and children without disabilities had lower diversity and intensity in skill-based activities. As has previously been reported, children in urban areas tend to spend more time in formal organized activities compared to children living in rural areas (43, 109-111). The reason for this may be that in urban areas there is a higher array of these kind of activities in combination with less available playing space and fewer safe neighbourhoods characteristic which means that children in urban areas are oblige to more formal activities than children in rural areas (43, 109-111). This result was also found in the semi-structured group interviews, where children living in rural areas more often mentioned doing activities outdoors and showed disappointment at not having access to nearby organized activities.

5.2.2 Generic personal factors influence participation in leisure activities

Results from Studies II and III confirmed findings from other studies indicating that personal generic factors such as age and gender will influence a child's pattern of participation (7, 12, 37, 40, 80, 98). It was demonstrated in Studies II and III that younger children with and without disabilities participated in a high diversity and

intensity of recreational activities. A plausible reason for the higher involvement of younger children is that the content of recreational activities in the CAPE/PAC is aimed more for younger children, and includes such activities as doing puzzles, playing with toys, doing crafts, and playing on playground equipment. Additionally, participation in informal recreational activities often requires less planning by, and assistance from, family members than formal organized activities, which means that children can easily participate in such recreational activities by themselves at home. This might explain the results from Studies II and III where Swedish and Norwegian children with disabilities participated in a higher number of recreational activities than children without disabilities.

Gender was the main predictor influencing diversity and intensity in physical and skill-based activities in children with and without disabilities in Studies II and III. This result was confirmed from other studies, where boys seem to be more involved in physical activities whereas, girls tend to participate more in skill-based activities (7, 12, 37, 40, 76, 80). The findings by Petronyte that showed that the association between low engagement in physical activities and psychological complaints was mediated by individual factors are of concern. Being a girl of older age was found to be the mediator for this association (41). Research has suggested that providing female classes, offering alternative, non-competitive forms of physical education (PE), and providing girls with greater autonomy are easy, realistic ways in which PE could be changed and which would improve girls' long-term participation in physical activities (99, 183) Furthermore, to be active in sports requires that the child possesses the necessary skills to successfully perform the activity, which in turn will influence the child's belief about how good he or she is at the activity and the expectations for success (63, 183). The child's self-efficacy will drive the child to find situations in which he or she can build and express their competencies as well as interests. This emphasizes the need to provide girls and children with disabilities opportunities to strengthen skills and their self-efficacy in physical activities (63).

Concerning generic sociodemographic factors, the results from Study II indicated that differences in the mother's level of education were associated with the child's diversity and enjoyment in social and physical activities, implying that higher parental education could explain participation in more diverse activities and increased enjoyment. The results from Study III also confirmed that a lower level of education was associated with less intensity in physical and skill-based activities in children with and without disabilities. Other studies have demonstrated that parental education influences social participation with people other than family members and participation in formal activities, but children to parents with higher education participated more frequently with others in these activities and experienced increased enjoyment (37, 76, 83, 98, 184). These findings indicate the importance of understanding parental influences on the child's participation. Especially for children with disabilities, it is suggested that parents with higher education may have more ideas about participation options for their children, more knowledge of and ability to access organized leisure, knowledge of how to access additional support services, and higher competencies in using electronic and print media to locate and access community resources (5, 83, 98). It is crucial, therefore, that therapists use strategies to promote the child's community participation by assisting families in identifying meaningful activities and resources that fit the child's abilities and interests (83).

5.2.3 Disability specific factors influence participation in leisure activities

When looking at disability-specific factors, it was found in Study II that occurrence of disability was associated with a higher diversity in all activity types except for physical activities, where no significant differences existed. In regards to the intensity of participation, the pattern was reversed and children with disabilities participated with less intensity in all activity types except for recreational activities compared to children without disabilities. In addition, children with disabilities seemed to have a higher enjoyment in recreational and self-improvement activities than children without disabilities

Further, differences between children with and without disabilities were also confirmed in the international Study III. The results of this study indicated that the Dutch children with disabilities participated with less diversity and intensity in all activity types compared to Dutch children without disabilities. For the Swedish and Norwegian children with disabilities, dissimilarities were found mainly in the intensity of activities performed often. Swedish and Norwegian children with disabilities participated with lower intensity in physical and social activities than children without disabilities. These results indicate that the occurrence of disability primarily influenced the intensity of the child's performance and are in accordance with results from other studies (5, 14, 24, 34, 42, 80, 108, 114, 185). The lower intensity in participation in leisure activities among children with disabilities can have many causes and it may be the combined impact of generic personal and environmental factors and disability specific factors, rather than single factors that have the largest influence on the child's outcomes. Different policies and legislation directed to assistive technology, equality of information, support and care services etc. might be important factors that influence the patterns of participation of children in the different countries. In Sweden, The Act Concerning Support and Service, LSS, is aimed at people with extensive disabilities that cause significant difficulties in daily life. The Act offers ten different activities, among them support and advice, personal assistance, escort service and a contact person. Norway has a similar system for support and service, and the children's possibility to participate in activity is pointed out as an important area for rehabilitation as well as integration in schools and leisure time (26, 106, 186). In the a cross-sectional European study of children with CP the inability to walk, occurrence of pain, low communication and intellectual ability were significantly associated with lower participation (58). In a Canadian study of participation in children with disabilities, about a third of the variation in recreation and leisure could be explained by the combined influences of the child's behaviour, impairment, and family recreational styles (178). Thus, participation-focused assessments and interventions probably need to be based on a multidimensional assessment of participation as well as a multidimensional assessment of personal and environmental factors. These findings suggest the need for careful investigation of factors that are barriers to participation for individual children to be able to implement effective intervention strategies for enhanced participation

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5.3 A MODEL OF CLIENT-CENTRED INTERVENTION TO INCREASE PARTICIPATION

Leisure is associated with free time when children have choices to do something fun. To provide and facilitate healthy engagement in leisure activities for all children regardless of, gender, socioeconomic background, or individual disorders is a key concern of occupational-centred practice for children and is consistence with an

occupational justice agenda (2). Even so, the focus of rehabilitation for children with physical disabilities has not been on participation in leisure activities but instead on mobility and independence in self-care (34, 125). In a study by Thomas and Rosenberg, it was found that paediatric physiotherapists and occupational therapists may not be practicing at an optimal level in terms of their degree of awareness of potential barriers that can hinder their clients' participation in leisure and community recreation. It was suggested that to optimally use intervention methods to promote participation in community and recreation, therapists need more information on the impact of barriers on the type and level of participation an individual child experiences and the relationship of these barriers to specific activities (187) . Generic factors and disability-specific factors have been shown in this thesis to exert an influence on participation depending on the activity type (recreational, social, physical, skill-based, or self-improvement). Various factors were the main predictors for the child's pattern of participation and thus influencing factors need to be assessed separately depending on the type of leisure activity in question.

Previous studies have demonstrated that to be engaged and find pleasure in leisure activities requires the child's autonomy in choosing a preferred activity and his/her intrinsic motivation to participate in the activity is important for the outcome (1, 100). Consequently, in the intervention study in this thesis it was vital to use a model of intervention that could handle the complexity of the objective and the subjective dimensions of participation and could emphasize the child's autonomy and intrinsic motivation. In the implemented intervention (Study IV) the objective dimension of participation was evaluated concerning goals of frequency of attending jujutsu training and in the number of letters written to a pen pal, whereas the subjective dimension was pertaining to the child's self-efficacy in goal performance. Moreover, previous studies have reported that interventions with the aim to improve participation in children should enhance the child's autonomy and empowerment (81, 138).
The implemented intervention, therefore, was based on a goal-directed client-centred approach. The children expressed their interests and were involved in decision making of goal activities and discussions of strategies that were used, all written down in logbooks throughout the intervention to promote the child's self-determination and autonomy.

The use of the GAS as an outcome measure stimulated the empowerment of the child by improving the clarity of the therapy objectives for both the therapists and the children. It was essential to find goals that were balanced between what the child could hope for and what was clinically relevant and realistic (146). Consequently it was essential for the therapists to carefully examine personal and environmental factors that might help or hinder participation. For therapists to enable the child to find challenging, internally motivated leisure activities, it is required that they have knowledge about the child's preferred niches, skills, and competences. Additionally, if the goal was self selected and realistic, it was hypothesized that the child's self-efficacy would increase when the child improved certain skills required for goal attainment. Moreover, it was assumed that functional training and constructive feedback could strengthen valuable skills and competences that would reinforce the child's self-efficacy to handle a certain situation. In turn this would stimulate the child to seek out new niches and increase his/her participation in leisure activities. In this study, the boys' estimation of performance ability and self-efficacy concerning their perceived ability to reach the specific goal increased over time, and the increased feeling of competence may have strengthened other participatory experiences (138). The results showed that after the

intervention one of the boys was no longer afraid of occupying a new niche and he began to practice tennis once a week.

The intervention model also included training of social skills because previous work has suggested that discussion groups with peers can be helpful in enhancing social participation for children with Asperger's disorder (139, 140) (188).
In the intervention, the children were active in the group discussions concerning different aspects of how a good friend should be, what to do together with a friend, how to make contact with a peer, and how to present one's strengths/skills/abilities and interests and they acted out the situations discussed. The possible positive effect of the social training cannot be confirmed, but the result from the follow up survey indicated that the boys had increased their knowledge of being together with peers by attending the group meetings and the parents found their boys to have become more socially active.

In this intervention study, the CAPE and PAC were found to be efficient self-reported assessments in surveying the child's pattern of participation and in finding preferred goal activities. Moreover, individualized outcome measures were crucial when evaluating outcomes identified by the child. The GAS, the COPM performance scale, and the estimations of self-efficacy provided individualized outcomes that were well suited to evaluate these changes. Palisano et al. have also reported satisfying results when using the GAS and COPM as outcome measures in their participation-based intervention study (81).

In conclusion, the results of this study indicated that the goals were attainable and that the intervention model was useful and efficient given that the two children attained their leisure activity goals and estimated higher performance ability and a greater self-efficacy at the end of the intervention. Moreover a client-centred approach where therapists use individual strategies to promote participation based on the child's motivation and empowerment seems to be important in improving participation in leisure activities.

5.4 METHODOLOGICAL CONSIDERATIONS

When changing the item contents in the Swedish version of the CAPE, it could be argued that the modified version would not be applicable to comparing participation outcomes of children between countries. But in view of the results from this thesis, it was demonstrated that cultural differences existed between countries, which needed to be taken into account, because comparisons might be misleading if some of the scored activities in the CAPE were irrelevant in one of the compared cultures.
. Hence, by using the Swedish version of the CAPE the outcome of the standardized mean diversity score for all activity types were significantly higher compared with the outcome of the original version. This is of course due to that activities that are relevant in a culture are more likely to be performed than activities that are not common in the investigated context. For example, children in Sweden are not familiar to the concept of "voluntary work", and thus do not answer that they perform this activity. However, another social leisure activity not represented in the CAPE, "Going to a café/restaurant" was performed by 78% of the Swedish children. Including context relevant activities makes the outcome more valid for Swedish children. Accordingly, when comparing the diversity and intensity scores of the Swedish, Norwegian, and Dutch children with and without disabilities, the results

indicated that the differences in the patterns of participation would have been even greater if the Swedish version of the CAPE had been used for Swedish children. This highlights the concerns of the cultural applicability of the item content in the CAPE and possible bias of results when using the original version of the CAPE/PAC which was not culturally adjusted to any of the three participating countries. In study III the original version of the CAPE was used according to the coauthors wishes, but to get a more appropriate description of children's patterns of participation in leisure activities in different countries a cultural validate version for each country would perhaps have produced other results. By using the original version of the CAPE differences between countries may have been underestimated, or equally likely, overestimated.

The selection of the item content in the Swedish version of the CAPE needed methodological considerations because participation is a multidimensional construct, often with low correlations between items, and the classic psychometric approach with analyses of internal structures was not ideal when adopting the CAPE (demonstrated in the results with low Cronbach's alpha values). Instead a clinimetric approach was used, and the selected items in the Swedish version were based on face validity by the judgments of researchers and the results from group interviews and field tests with children (95, 96, 176). Research has demonstrated that the two disparate approaches select different items (97, 189). Clinimetric methods have a propensity to identify items that are relevant and important to patients and reflect several characteristics that together define a construct, whereas a psychometric approach identifies items that measure single characteristics or attributes of the construct (97, 189). Given these differences and depending on the construct, investigators may find one strategy more appealing than the other (189). In this thesis, it was important to identify a variety of leisure activities, that were important to Swedish children, irrespective of their association with each other, and therefore the clinimetric approach appeared to be the most appropriate method.

The results from Studies II and III indicated that the set of independent variables in the multiple regression analysis could only predict or explain a low to moderate variance in the participation outcome. Probably additional personal and environmental factors need to be added to the model such as functional level, communication skills, self-efficacy, autonomy, transportation, availability and accessibility of activities, and parent's preferences for activities to receive a higher explanatory value. The sample size of 55 children with disabilities in Study II did not allow the inclusion of more than five independent variables due to the difficulty in controlling for type I error. The lack of adequate measure instruments covering the other potential influencing factors is also a problem.

Another consideration is the way in which participation has been measured in this thesis. The CAPE is not an optimal measure of the subjective dimension of participation because it does not really capture the child's engagement and autonomy while performing an activity. Instead, additional research methods are needed based on qualitative methodologies such as interviews with children and observations of children's leisure time. As an example Maxwell et al (2012) used random calls to pagers to signal children to provide self-reports of both dimensions of participation, i.e., presence (frequency of attending) and engagement in the here and now situation (75) Longitudinal studies using self-reports can provide essential information about interaction with personal and environmental factors that might change the child's patterns' of participation over time (136).

Other limitations of this thesis concerned the data collection of the included children. In Study I the representativeness of the sample might be low because it was not based on a random selection of children recruited from all parts of Sweden. This approach was not feasible, but the strategic selection of children that represented different socioeconomic backgrounds, geographic living areas, ages, and gender, which are all factors that influence patterns of participation, were taken into consideration in the constellations of group interviews and field tests (10, 33, 37, 114, 190).

In Study II, the relatively small sample and the non-random selection of children with disabilities might have influenced the results. The therapists who recruited these children might have sent the questionnaire primarily to children who they knew were active in leisure activities. Thus, the responders may not be representative of the population of children with disabilities. Furthermore, the response rate among children with disabilities was only 50%, and it is possible that the families who responded were more active in leisure activities than families that chose not to respond.

Concerning Study III, the lack of information as to whether the samples of children with disabilities have similar functional levels is a limitation, even though the inclusion criteria were comparable in all three countries. Studies of children with CP have demonstrated that a lower level of functioning is correlated with lower participation level (10, 11, 14, 58, 84). The results of this study showed that the Scandinavian children with disabilities had a higher level of participation in leisure activities than the Dutch children, indicating that they may also have a higher functional level. But when comparing the GMFCS levels for children with CP, 37.5% of the Swedish and 60.0% of the Norwegian children had a GMFCS level I-II compared to 71.5% of the Dutch children. This means that factors other than the child's functional level probably must be the explaining factor behind the children's diversity and intensity of participation. However, functional classifications for gross motor function, manual ability, and communication such as the GMFCS (191), the Manual Ability Classification System, MACS (192) and the Communication Function Classification System, CFCS (193) are available only for children with CP. On average, 60% of the sample had other diagnoses than CP, so evaluating if these classifications could be used for other populations of individuals with functional limitations would be valuable. Other factors, such as social skills and autonomy, also need further consideration when selecting assessment instruments, classifications, and research methodologies (194, 195).

The sample size in study IV included only 2 children with neuropsychiatric disabilities. This is a small sample this and can, of course, be seen as a limitation and make it difficult to draw general conclusions. The intervention had a single subject design and the aim was not to draw general conclusions of all children with neuropsychiatric disabilities, but rather too evaluate the efficacy of a new intervention model. Moreover, an intervention concerning a multidimensional construct like participation requires individualized components that are focused on the child's needs and often involve several disciplines. The outcome, therefore, is often not the product of a single component, but is a result of multiple factors (136). This means that randomized controlled trial designs are not the best option because these designs are more appropriate for interventions that are unidimensional and controllable. Furthermore, the results of randomized control trials are based on pooled data and do not show the intervention effects among individuals (136, 159, 196). Instead, when implementing an intervention dealing with a multidimensional construct and individualized treatment strategies quasi-experimental or qualitative designs are better options(136). Single-

subject designs have proven to be ideal for monitoring and evaluating practice effectiveness on a day-to-day individual basis, and to be sufficient designs for use as the first step when developing and testing a new intervention (159).

Another consideration was the use of the GAS as an outcome measure in the intervention study. The literature has demonstrated that the GAS can be an essential and sensitive individualized outcome measure to be used in rehabilitation interventions (153, 155) . The goal scales in study IV, however, still leave room for improvements. Even though the therapists received education in using the GAS, they found it difficult and time consuming to define goals. The literature has stated that practice is needed to successfully use the GAS and it can be difficult to differentiate the goal activity at different levels (153). The experiences from this study indicate that a careful inventory of barriers and facilitators for goal activity is essential for the effective use of the GAS, and that the therapists needed more education and practice in using this assessment tool.

5.5 CONCLUSIONS AND IMPLICATIONS

This thesis reports evidence that a cultural validation of the CAPE was necessary and it was not enough to simply translate the CAPE, validation of the item relevance to the Swedish context was essential. The selection of the item content in the Swedish version of the CAPE needed methodological considerations because participation is a multidimensional construct. A clinimetric approach was used, and the selected items in the Swedish version were based on face validity by the judgments of researchers and the results from group interviews and field tests with children. After minor adjustment of some items, their content became clearer to the Swedish children. The fact that activities in the Swedish version were more applicable resulted in a higher standardized mean diversity score for the Swedish version than that of the original version of the CAPE, which indicates a more culturally valid version.

The conclusion drawn from this thesis is that the patterns of participation in leisure activities for children with and without disabilities are a product of a continual process between the child and the influences from several personal, environmental, and disability-specific factors in the child's bio-ecological systems, rather than single factors such as impairment, parental education, age, or gender. Further, the results demonstrated that the five activity types were influenced in part by different factors. The occurrence of disability seems to mainly influence the intensity of the participation in leisure activities, thus Swedish, Norwegian, and Dutch children with disabilities participated with a lower intensity than children without disabilities. The personal generic factor age influenced the enjoyment and the diversity of activities performed, and younger children tended to participate in a higher number of activities and experience a greater enjoyment compared to older children. A difference in patterns of participation influenced by gender that had been seen in other studies was also confirmed in this thesis. Boys tended to prefer to participate in physical activities whereas girls tended to be more active in social, skill-based, and self-improvement activities.

Longitudinal studies of participation in leisure activities are essential to increase the knowledge of changes over time in children's preferences for activities. Further

analysis of the physical accessibility, community programs, and the causes of nationality heterogeneity are essential to provide evidence for changes to national legislation and policies that promote participation for children with disabilities.

Finally, the implemented intervention with a client-centred approach facilitated children with neuropsychiatric diagnosis deciding and attaining leisure activity goals that were important to them. The result showed that at the end of the intervention the children had achieved higher performance ability and a greater self-efficacy in the performance of the activity. The CAPE and PAC were efficient self-reported assessments in this work. Findings from the intervention study suggested that it was essential to carefully analyse personal and environmental barriers and facilitators for children's participation, because this will provide the therapist with ideas as to which strategies should be implemented for goal attainment. A client-centred approach involves the therapists stimulating the child to find internally motivated goal activities, motivating the child and giving positive feed-back, creating an understanding of the intervention process, and supporting the child in decision making, and these components appear to be important in enhancing the child's participation in leisure activities.

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Den mätta dagen är aldrig störst.
Den bästa dagen är en dag av törst.

Nog finns det mål och mening i vår färd,
men det är vägen, som är mödan värd.

Det bästa målet är en nattlång rast,
där elden tänds och brödet bryts i hast.

På ställen, där man sover blott en gång,
blir sömnen trygg och drömmen full av sång.

Bryt upp, bryt upp! Den nya dagen gryr.
Oändligt är vårt stora äventyr.

Karin Boye 1927

7 REFERENCES

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