Participation in leisure activities of children and adolescents with physical disabilities

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Participation in leisure activities of children and adolescents with physical disabilities

Participatie in vrijetijdsactiviteiten van kinderen en adolescenten met een lichamelijke beperking

(met een samenvatting in het Nederlands)

Proefschrift

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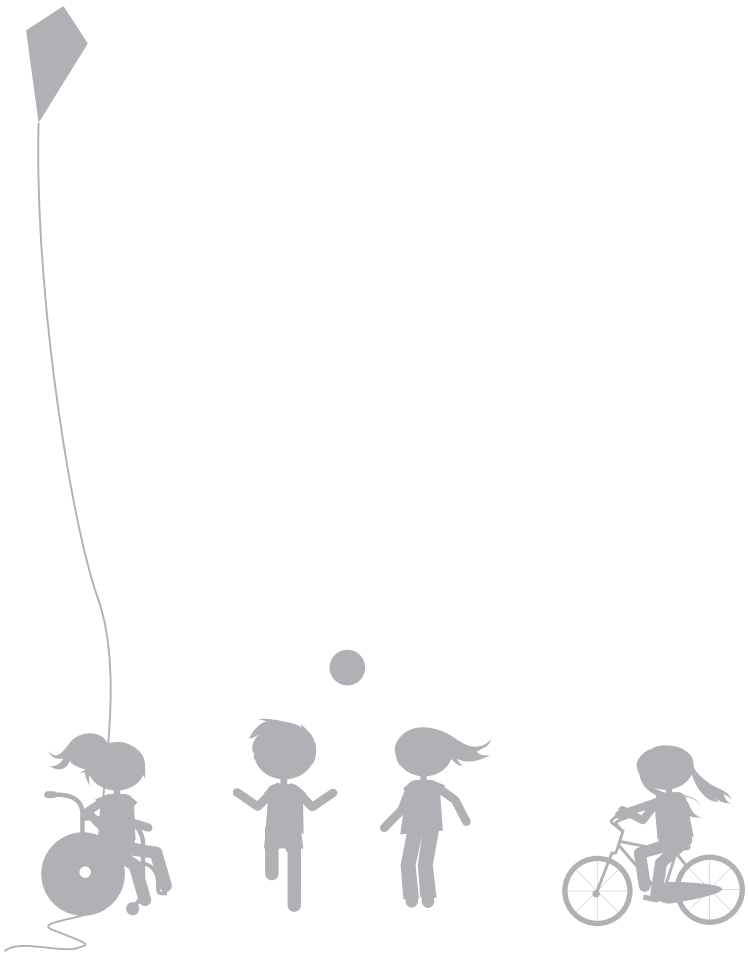
'Wat er ook speelt in een land,
laat het vooral de kinderen zijn.'
(Loesje)



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Chapter 1

General introduction

In the Netherlands it is estimated that 7-12% of the children aged 0-19 years have physical problems due to a chronic disease or physical disability (de Klerk, 2007; Zeijl, 2005). About 98,000 (2-7%) children experience minor restrictions because of their physical condition. Around 74.000 (1-3%) of them experience severe restrictions in their daily functioning because of a chronic disease or physical disability (de Klerk, 2007).

The majority of children with physical disabilities[1] experience restrictions in their daily functioning due to conditions that are present from birth. With a prevalence of 2.5 per 1000 live births Cerebral Palsy (CP) is the most common cause of physical disability in children (Johnson, 2002). Other possible causes of physical disability in children are juvenile idiopathic arthritis, spina bifida and neuromuscular diseases (de Klerk, 2007). All of these diagnoses have in common that they cause functional limitations in daily life. Because of these functional limitations the course of development of children with a physical disability is different from that of their typically developing peers. Children with more severe physical restrictions have more problems in functioning in daily life, including problems with mobility (Kerr, McDowell, & McDonough, 2007; Palisano et al., 2003; Smits et al., 2011). Personal care, communication and engaging in social relations, going to school and undertaking activities in the community are more restricted for children and youth with more severe physical disabilities (Lepage, Noreau, & Bernard, 1998). The more severe the physical disability, the more frequent additional neuroimpairments like epilepsy, hydrocephalus and visual impairments, occur. For example, 53% of children with CP were found to show additional neuroimpairments (Beckung & Hagberg, 2002). Children with a physical disability are also known to be at risk for psychosocial problems. Compared to their typically developing peers they have more behavioural problems, emotional problems, are more often hyperactive and have problems in peer relations (Brossard-Racine et al., 2012).

International Classification of Functioning (ICF)

In order to describe human functioning, possible limitations in human functioning and interrelations between determinants of functioning, the World Health Organization (WHO) has published the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001). The ICF was designed for multiple purposes including "… providing a scientific basis for understanding and studying health and health-related states, outcomes and determinants" and "…to permit comparison of data across countries, health care disciplines, services and time" (p. 5). In 2004 the WHO published the International

1 Instead of 'physical disabilities' the international Classification of Functioning (ICF) also uses 'physical impairment' to describe functional limitations. These terms may be used interchangeably. In this thesis 'physical disability' will be used throughout.

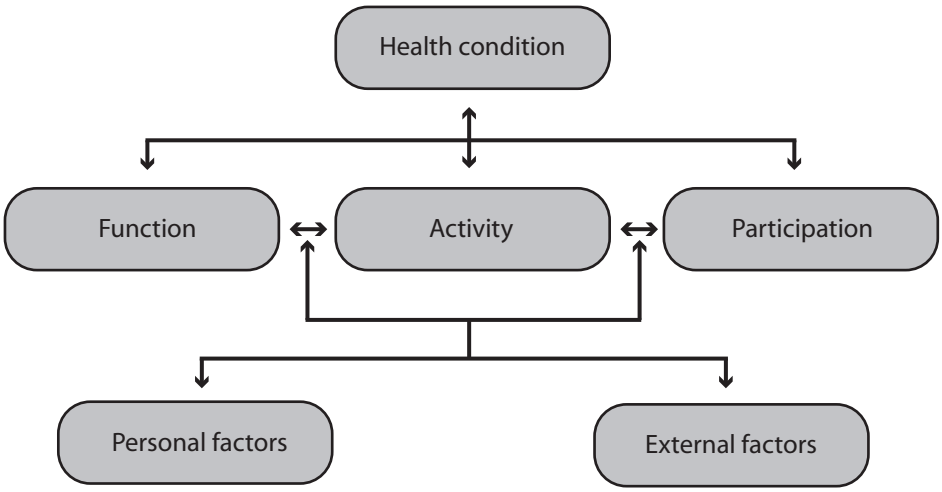

Figure 1.1 International Classification of Functioning (ICF).

Classification of Functioning Disability and Health Child Youth version (ICF-CY) (World Health Organization, 2004). This classification incorporates the context of the environment of children and their developmental continuum. The rapid physical and emotional growth children and youth encounter in the first decade of their lives is incorporated in more detail. The ICF consists of several components describing function and disability (body functions and structure and activities and participation) or contextual factors (environmental and personal factors). Figure 1.1 shows the different components of the ICF.

In the ICF the different components of human functioning are assumed to be interrelated showing the complex interplay of human functioning with environmental and personal factors. Problems in functioning also affect participation in different activities. Participation has been defined (World Health Organization, 2001) as 'someone's involvement in life situations'. Life situations include going to school, engaging in social contact and being involved in activities in a person's free time. Free time and leisure activities are of major importance to children: it is the context in which they develop skills, socialize with peers, explore personal interests and enjoy life (Simpkins, Ripke, Huston, & Eccles, 2005).

Leisure activities

Leisure activities can be defined as freely chosen activities performed when not involved in work or school (King, Law, King, Rosenbaum, Kertoy, & Young, 2003; King et al., 2007). More specifically '… everyday activities of childhood in all types of non-school environments,

including environments for play, sport, entertainment, learning and religious expression' (King et al., 2003, p. 65). Different types of activities can be distinguished. Activities that are structured and involve rules or goals and have a formally designated coach or leader are called formal activities. Activities that require little or no planning and are often initiated by the child are called informal activities (King, 2003; King et al., 2007).

Being involved in leisure activities is of major importance to the development of children. It not only allows children to develop skills and engage in social contact with others. Research has shown that children that participate in formal out of school activities are more self-confident, have a better social network and perform better in school (Brown & Gordon, 1987; Larson & Verma, 1999). Participation has a positive impact on the self-esteem and behaviour of children (Moons et al., 2006). Moreover, participating in activities leads to a higher quality of life in mental, physical and social domains (Dahan-Oliel, Shikako-Thomas, & Majnemer, 2012; Mc Manus, Corcoran, & Perry, 2008). Finally, parents, youth and professionals consider enhanced participation in leisure activities as one of the most important outcomes of intervention (Vargus-Adams & Martin, 2010).

Children with physical disabilities

Children with physical disabilities are at risk for experiencing limitations in their daily life including difficulties to participate in leisure activities (Maher, Williams, Olds, & Lane, 2007; Østensjø, Carlberg, & Vollestad, 2003). They participate less in leisure activities than their non-disabled peers (Imms, 2008a; Shikako-Thomas, Majnemer, Law, & Lach, 2008) and their activities are more often home based, more passive and show less variation (Shikako-Thomas et al., 2008).

Child-, family- and environmental variables all play an important role in the achieved level of participation. For example, age, gender and family socio-economic status are associated with frequency and level of participation in leisure activities. Children aged 6 to 8 years participate in more, and more diverse, recreational and informal activities than children aged 9 to 14 years. Boys tend to participate more in physical activities while girls participate more in social and skill-based activities (Law et al., 2006). Finally, lower family income and lower parental educational level are related to participation in fewer activities.

Participation of children with physical disabilities – current gaps

Since the publication of the ICF in 2001 more and more research has focused on the concept of participation and the determinants of leisure participation for children with physical disabilities. However, most research has been diagnosis specific and may not reflect determinants for the whole group of children and youth with physical disabilities. There is a need for research

incorporating several diagnoses of physical disabilities to see, for example, whether the determinants for children with CP are also applicable for children with other diagnoses (Shikako-Thomas et al., 2008).

In order to get a comprehensive understanding of factors related to participation, first and foremost valid and reliable measures are needed. Currently, several instruments are available for measuring participation in children and youth. Validity, reliability and clinical utility differ for these measures (Sakzewski, Boyd, & Ziviani, 2007). It is suggested that participation measures are most suitable when they ask the child directly and measure the actual performance in leisure activities instead of the assistance needed by the child to accomplish an activity (McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006). A range of measures is available to measure participation but not all measure performance in activities directly reported by the child. An example of a measure that does incorporate these characteristics is the Children's Assessment of Participation and Enjoyment (CAPE). The CAPE aims to measure participation in leisure activities (Imms, 2008b; King et al., 2007). The CAPE has been validated in a large group of children with physical disabilities in Canada. Research has shown the CAPE to be a valid and reliable measure for children with physical disabilities. Although the CAPE has been used for measuring participation in other countries, validity and reliability have not been established outside Canada. Since environmental factors (physical, social and attitudinal) play an important role in participation in leisure activities not all measures might be useful across countries. Before examining determinants of participation of Dutch children with and without physical disabilities in more detail validity and reliability need to be established.

An accompanying measure of the CAPE is the Preferences for Activities of Children (PAC) (King et al., 2007). This measure assesses the preference for activities of each individual child. Literature has shown that preference is an important determinant of participation (Imms, Reilly, Carlin, & Dodd, 2009; King et al., 2006; King et al., 2009). The higher the preference, the higher participation in activities. However it is not known whether children with a physical disability are able to participate in activities they prefer. Because of the physical restrictions they encounter in their daily life not all activities may be suitable or accessible. As a result they may experience a discrepancy between the activities they prefer and actually engage in. Not being able to do what you prefer may have harmful consequences for your well-being.

Participation varies with age and therefore measures should also be specified for different age groups. Most studies have focussed on children aged 6 to 18 years. Measures suitable for preschool children are scarce and only recently some were developed. Measuring participation at a young age is important because it has predictive value for later participation. A longitudinal study among non-disabled children shows that patterns of participation are established early in life and maintain

relatively stable into adolescence (Findlay, Garner, & Kohen, 2010). Identification of participation problems early in life could help guide interventions for children with physical disabilities.

Aims and outline of the present thesis

The general aims of this thesis are to describe participation in leisure activities of children and youth aged 2 to 18 years, with and without a physical disability, in the Netherlands and to identify determinants of participation.

The specific aims of this thesis are:

- To validate two measures for participation in the Dutch population across a wide age range for both children with and without a physical disability
- To assess determinants of participation both across a wide range of children with physical disabilities and specifically aimed at children with CP (literature review, prospective study, international comparison study)
- To assess the discrepancy between preference and actual participation in activities.

Outline of the thesis

Chapter 2 presents the validity and reliability of the APCP. This instrument measures participation of pre-school children aged 2 to 6 years. Chapter 3 describes the CAPE, an instrument for measuring participation in children and adolescents aged 6 to 18 years. The validity and reliability of this measure in the Dutch population of children and youth both with and without physical disabilities will be described. Chapter 4 describes the current literature on determinants of participation for children with a physical disability. Contrary to earlier reviews a range of diagnoses is incorporated in this review. Results are presented according to the ICF framework. Chapter 5, 6 and 7 describe studies in which the Dutch translation of the CAPE has been used to assess participation. Chapter 5 describes a prospective cohort study in which data of young children (2 years of age) with CP are related to participation when the children are school aged (6-8 years of age). Chapter 6 concerns a comparison between Spanish and Dutch children with CP and their healthy peers describing their participation and determinants of participation. In chapter 7 a cross sectional study describing the discrepancy between children's preference for activities and their actual participation in leisure activities is presented. The thesis concludes in chapter 8 with a summary and general discussion of the reported findings. After summarizing the main findings the implications for research and clinical practice are discussed, together with methodological aspects of the studies.

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Chapter 2

Psychometric evaluation of the Dutch version of the Assessment of Preschool Children's Participation (APCP): Construct validity and test-retest reliability

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Submitted for publication

ABSTRACT

Participation in activities provides opportunities for preschool children to develop skills, engage in social contacts and has a positive impact on mental and physical well-being. The aim of this study is to examine construct validity and test-retest reliability of the Dutch translation of the Assessment of Preschool Children's Participation (APCP) A participation measure for children aged 2 to 5 years and 11 months with and without physical disabilities. A group of 126 parents of children participated in the study; 67 children without physical disabilities and 59 children with physical disabilities Construct validity was tested using three hypotheses that could all be confirmed. Although not for all activity types. ICCs for test-retest reliability were good to excellent. The Dutch translation APCP can therefore be considered a valid and reliable measure of participation for preschool children with and without physical disabilities.

INTRODUCTION

Participation is defined by the World Health Organization as "involvement in life situations" (World Health Organization, 2001). Participation provides opportunities for children to develop skills, creativity, and a social life, builds self-esteem, leads to more social support, has a positive impact on mental and physical well being, and contributes to quality of life (Almqvist, Hellnas, Stefansson, & Granlund, 2006; King et al., 2003; Larson & Verma 1999; Mc Manus, Corcoran, & Perry, 2008; World Health Organization, 2001).

In the past few years, numerous studies have been dedicated to participation of children and youth with physical disabilities. These studies have shown that children with physical disabilities are more restricted in their participation than children without physical disabilities. They show less variation in participation, have fewer social engagements, and spend more time in quiet recreational activities (Imms, Reilly, Carlin, & Dodd, 2008; Majnemer et al., 2008; Shikako-Thomas, Majnemer, Law, & Lach, 2008). The majority of these studies include children starting from the age of 6 (Bult, Verschuren, Jongmans, Lindeman, & Ketelaar, 2011; Imms, Reilly, Carlin, & Dodd, 2009; Shikako-Thomas et al., 2008). Studies looking at participation of preschool children are scarce while the preschool age is vitally important for the children's development and for establishing interest and active involvement in a variety of activities. The foundations for meaningful participation are most likely established in the first years of life.

Research has shown that for a substantial number of children their participation level remains stable from early childhood into adolescence (Findlay, Garner, & Kohen, 2009). It is also known that families of young children with a disability encounter participation problems in their daily life (Rentinck, Gorter, Ketelaar, Lindeman, & Jongmans, 2009). Forty five percent

of the parents felt restricted in their family participation and this percentage increases when the child get's older. Family participation when the child is preschool aged has shown to be a strong predictor of later participation for children (Bult et al., 2012).

Recently, several assessment tools for measuring preschool children's participation have been published (Kemps, Siebes, Gorter, Ketelaar, & Jongmans, 2010; Law, King, Petrenchik, Kertoy, & Anaby, 2012; Rosenberg, Jarus, & Bart, 2010). One of these is the Assessment of Preschool Children's Participation (APCP) (Law et al., 2012). The APCP assesses participation in day-to-day activities of preschool children. It is a standardized, parent- completed measure of participation for children aged 2 to 5 years and 11 months. A total of 45 activities are included for measuring participation in play, skill development, active physical recreation and social activities. This measure is modelled after the Children's Assessment of Participation and Enjoyment (CAPE) that has shown good psychometric properties for measuring participation in leisure activities (King et al., 2007). Like the CAPE, drawings of everyday activities are used to assess whether the child has done the activity in the past 4 months (diversity) and if so, how often (intensity).

The APCP has been shown to have good internal consistency and validity for children with cerebral palsy (CP) (Law et al., 2012). However, whether this measure is suitable for measuring participation in a larger population of preschool children with various diagnoses of physical disabilities remains unclear. Moreover, no comparison has been made between children with disabilities and healthy peers using the APCP. As stated before, children with a physical disability are known to participate in fewer activities than children without physical disabilities. A valid measure should be able to distinguish between these groups. In addition, test-retest reliability for the APCP has so far not been established. Only if a measure has proven to be valid in a larger population and shows good reliability, it can be used for clinical and research purposes. Moreover for use in another country, psychometric properties of measures need to be assessed in order to confirm applicability in the new context (Guillemin, Bombardier, & Beaton, 1993). Proper translation, back translation and review by experts needs to be carried out as well as testing of validity and reliability. Therefore the aim of this study is to examine construct validity and test-retest reliability of the Dutch APCP for children aged 2 to 5 years and 11 months with and without physical disabilities. In order to assess construct validity of the Dutch APCP we formulated three hypotheses based on previous reports in the literature.

First, it is expected that children with physical disabilities will demonstrate less diversity and less intensity in activities than children without physical disabilities: younger children participated mostly with their parents. Research has shown that parents of children with a disability felt

restricted in their family's participation and participate less in community activities compared to parents of children without disabilities (Ehrmann, Aeschleman, & Svanum, 1995; Rentinck et al., 2009). Moreover, it is known that children with a disability are less playful when they are young (Okimoto, Bundy, & Hanzlik, 2000). So, it can be expected that for activities outside the home as well as activities in the home, children with a disability will participate less frequently in fewer activities.

Second, it is expected that for both children with and without physical disabilities, boys and girls will participate equally in overall activities: differences in play behaviour between boys and girls are apparent from an early age, but these differences are described to be modest and limited to the use of a few toys instead of activities (Zosuls et al., 2009). Therefore these differences are not expected for specific activity types or an overall measure of participation. The APCP lists different kinds of activities that can be done by boys and girls and for every item examples for boys and girls are given. Moreover, the APCP looks at activities and not specific toys used by boys and girls.

Third, and finally, it is expected for both children with and without physical disabilities, older preschool children (4-5 years old) will demonstrate more diversity and more intensity in overall activities than younger preschool children (2-3 years old): children show a rapid growth in skills during the preschool years enabling them to expand their play and interests. From research it is known that children aged 5-6 years engaged in more reading, social interaction, and playing video games compared to children aged 2-4 years of age (Huston, Wright, Marquis, & Green, 1999). Rosenberg et al. (2010) have also shown that children aged 4-5 years of age engage in fewer tasks and do so with less independence than children aged 5-6 years do.

METHODS

Participants

A group of 126 parents of children aged 2 to 5 years and 11 months of age participated in the study; 67 children without physical disabilities (mean age 3 years 2 months, SD 1.2) and 59 children with physical disabilities (mean age 2 years 9 months, SD 1.8). As outlined in Table 2.1, gender and age of the children were equally distributed between the group of children with and without physical disabilities. Of the children with physical disabilities, the largest group (66.1%) had CP, 8.5% had developmental delay, and 6.8% had skeletal problems. Children with different diagnoses such as chromosomal or white matter deviation were classified in the category other. Most respondents were mothers (80.2%).

Table 2.1 Characteristics of children with and without physical disabilities (PD)

	Study sample		Children without PD		Children with PD	
	N	%	N	%	N	%
Total	126	100	67	53.2	59	46.8
Gender						
Male	67	53.2	34	50.7	33	55.9
Female	59	46.8	33	49.3	26	44.1
Age						
2-3 years	88	69.8	42	62.7	46	78.0
4-5 years	38	30.1	25	37.3	13	22.0
Diagnosis						
Central nervous system						
Cerebral palsy					39	66.1
Developmental delay					5	8.5
Spina bifida					3	5.1
Aquired brain injury					1	1.7
CNS other					2	3.4
Musculoskeletal						
Neuromuscular					2	3.4
Skeletal					4	6.8
Missing					2	3.4
Unknown					1	1.7
Respondent						
Mother	101	80.2	54	80.6	47	79.7
Father	16	12.7	11	16.4	5	8.5
Father and mother	7	5.6	1	1.5	6	10.2
Unknown	2	1.6	1	1.5	1	1.7

Procedure

The APCP was translated from English into Dutch and the suitability of all items for children growing up in Dutch society were discussed by the authors (MB, OV). As a result some minor alterations in wording were made to increase the readability of sentences and explanations of items were completed. None of the pictures were changed, nor were any examples added. All 45 items from the English version appear in the Dutch APCP. After processing these changes, the items were translated back into English by a professional translator (native speaker of the English language). The authors then compared this translation to the original English language version and concluded that the content of the translated questionnaire could be maintained.

Validity

To assess the validity of the Dutch APCP both parents of children with and without physical disabilities were included in the study. Parents of children without physical disabilities were recruited in two ways; a) through day-care centres in central Netherlands; b) through the social network of the research group. Parents of children with disabilities were also recruited in two ways; a) through therapeutic toddler groups and a school for special education of a rehabilitation centre in central Netherlands; b) parents of children that participated in the Learn2Move 2-3 (L2M 2-3) study between October 2009 and October 2011. For these children, the Dutch APCP was completed by one of the parents as part of a larger assessment battery, which parents completed at the start of the study (Ketelaar et al., 2010). For the other children that were included, the Dutch APCP was sent to the parents by mail together with an introduction letter, a consent form, a demographic form, and a postage-paid return envelope.

Inclusion criteria for children with and without physical disabilities were: (a) the age of the children was between 2 and 5 years and 11 months at the time of the study, (b) parents provided written consent for participation in the study.

Test-retest reliability

To establish test-retest reliability for the Dutch APCP, parents of both children with and without physical disabilities were recruited. They were sent the Dutch APCP for the second time approximately four weeks after they had filled in the first Dutch APCP. Parents that were recruited through the L2M 2-3 study did not participate in the test-retest assessment.

Measures

Dutch version of the Assessment of Preschool Children's Participation (Dutch APCP)

The APCP is a parent-completed questionnaire that measures the participation of children aged 2 to 5 years and 11 months (Law et al., 2012). It consists of 45 everyday activities subdivided into four activity types; play, skill development, active physical recreation, and social activities.

For every activity, parents are asked to indicate if the child performed that activity over the previous four months. If the child performed the activity, the parents reported how often the activity took place in the previous four months on a 7-point ordinal scale (e.g. 1 = '1 time in the past four months' and 7 = '1 time a day or more'.) Diversity scores were calculated by counting

the number of activities performed by the child over the past four months. The intensity of involvement in each activity was calculated by dividing the sum of item frequency by the number of possible activities for each activity type.

Demographic variables

Information about the child and family demographics were assessed by a short questionnaire containing information about gender, age, educational level of the parent and diagnosis of the child (if applicable).

Statistical analyses

The diversity and intensity of participation of each child were calculated for each of the four activity types of the APCP (play, skill development, active physical recreation, and social) and the total score. Descriptive statistics (mean and standard deviation) of diversity and intensity were calculated to describe the children's level of participation for each of the activity types. The hypotheses for assessing construct validity were tested using the independent samples T-test. Test-retest reliability was calculated using a Single Measure Intra Class Correlation (ICC). The ICC (two way mixed) was calculated for the intensity scores of all subscales and the overall scale score of the APCP. Correlations lower than .40 are considered to be poor, those between .40-.59 as moderate, good correlations range from .60 -.74, and excellent correlations are higher than .75 (Cohen, 1988).

RESULTS

Construct validity

Results of the differences between groups are presented in Table 2.2. Children with a physical disability participated in fewer activities and did so with lower intensity than children without physical disabilities, on all activity types. This confirms the first hypothesis in which was expected that children with physical disabilities would participate in fewer activities and do so with lower frequency. Boys and girls participated in an equally wide variety of activities and with similar frequency except for intensity of skill development. Girls participated more frequently in these activities than boys. For the second hypothesis no differences were expected between boys and girls. Therefore the hypothesis is partly confirmed. Children aged 4 and 5 years participated in more activities than 2 and 3 year olds and show a higher frequency on the total score. For activity types, age differences were significant for diversity and intensity scores on the total score on the skill

Table 2.2 Participation diversity and intensity of children without and with physical disabilities (PD), boys and girls and age groups on the Dutch APCP

Activity types	Diversity of participation, mean (SD)					
	Physical disability		Gender		Age	
	without PD N = 67	with PD N = 59	Boy N = 67	Girl N = 59	2-3 N = 88	4-5 N = 38
Total	**32.5 (5.1)*** **	**26.6 (6.4)**	29.4 (6.8)	30.2 (6.1)	**28.3 (6.2)** **	**33.1 (6.0)**
Play	**7.6 (1.3)*** **	**6.2 (1.6)**	6.9 (1.7)	7.1 (1.5)	6.8 (1.7)	7.4 (1.4)
Skill development	**9.7 (1.8)** **	**8.4 (2.3)**	8.9 (2.1)	9.3 (2.1)	**8.5 (1.9)*** **	**10.4 (2.1)**
Active physical	**7.4 (1.5)*** **	**5.6 (2.4)**	6.6 (2.2)	6.5 (2.1)	6.3 (2.1)	7.1 (2.2)
Social	**7.8 (1.7)*** **	**6.3 (1.9)**	7.0 (2.1)	7.2 (1.8)	**6.7 (1.9)*** **	**8.1 (1.7)**
	Intensity of participation mean (SD)					
	Physical disability		Gender		Age	
	without PD N = 67	with PD N = 59	Boy N = 67	Girl N = 59	2-3 N = 88	4-5 N = 38
Total	**3.5 (0.5)*** **	**2.9 (0.7)**	3.2 (0.7)	3.3 (0.7)	**3.1 (0.7)** **	**3.5 (0.7)**
Play	**4.6 (0.8)*** **	**3.9 (1.1)**	4.3 (1.0)	4.3 (1.0)	4.2 (1.1)	4.4 (0.9)
Skill development	**3.5 (0.6)*** **	**3.0 (0.9)**	**3.1 (0.8)***	**3.4 (0.8)**	**3.0 (0.7)*** **	**3.7 (0.8)**
Active physical	**3.3 (0.8)*** **	**2.5 (1.2)**	3.0 (1.1)	2.9 (1.1)	2.9 (1.1)	3.0 (1.0)
Social	**2.9 (0.7)*** **	**2.4 (0.8)**	2.6 (0.8)	2.7 (0.8)	**2.5 (0.8)** **	**2.9 (0.7)**

Bolded text shows significant difference between the groups.
*$p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

development and social activities. The results confirm the third hypothesis in which was expected that older children would participate in more activities and do so with a higher frequency overall.

Test-retest reliability

The mean time between the first and second completion of the Dutch APCP by parents was 38 days (SD = 20). Table 2.3 shows the correlations coefficients for the overall diversity and intensity score and the four subscales scores for both the total group and the groups without and with physical disabilities. The ICCs for overall participation were excellent for diversity and intensity for both children with and without physical disabilities (.83-.91). For the different activity types, ICCs ranged between .63 and .86, which can be considered good to excellent.

Table 2.3 Test-retest reliability ICCs for diversity and intensity scores of the Dutch APCP for the total group and for the groups of children without and with physical disabilities (PD)

		Activity types			
	Overall participation	Play	Skill development	Active physical	Social
Diversity					
Total (N = 72)	.91	.76	.83	.83	.83
Without PD (N = 48)	.89	.74	.86	.73	.76
With PD (N = 24)	.88	.68	.77	.84	.87
Intensity					
Total (N = 72)	.86	.74	.75	.81	.82
Without PD (N = 48)	.83	.75	.81	.74	.78
With PD (N = 24)	.85	.63	.67	.85	.82

DISCUSSION

In this study the construct validity and test-retest reliability of the Dutch APCP were examined. Construct validity was measured by examining hypotheses based on the recent literature. Looking at the total score for diversity and intensity of activities performed by children with and without disabilities, all hypotheses were confirmed. Looking at the activity types, not all hypothesis could be confirmed for all activity types. The test-retest reliability was good to excellent with ICCs ranging from .63 to .91 for all groups and all activity types. These findings indicate that the Dutch APCP is a reliable and valid instrument to measure the participation of children with and without physical disabilities aged 2 to 5 years and 11 months.

For the various activity types, not all hypotheses were confirmed. Although no differences were expected between boys and girls, girls participated more intensely in development activities than boys. A similar finding has previously been reported in older and adolescent girls (Majnemer et al., 2008). Probably, contrary to what was expected, differences in activities between boys and girls are more apparent at a young age and not only in an older population. Furthermore, differences between age groups were only observed for skill development and social activities, but not for active physical and play activities. Older children participated more in skill development and social activities. Skill development activities consist of activities like music and swimming lessons and activities done in the community. Social activities consist of activities like going to the movies and having someone over to play. For both activity types, it can be expected that 4-5 year olds would engage in them more frequently than 2-3 year olds because they are more independent and have more skills to do these activities. This shows that the APCP is representing a range of activities suitable for the whole age range of the APCP.

In this study, differences are proven between children with and without physical disabilities on both the number of activities they engaged in as well as the intensity of their engagement. This finding is in line with other recent studies comparing young children with and without physical disabilities (Kemps et al., 2010; Rosenberg et al., 2010). If this pattern of participation in few activities at low intensity is prevalent in young children with disabilities, it will be important to begin to promote participation early for those children with restricted participation. This is not to say that more participation is necessarily better, but children who are active in different activities have more potential opportunities to learn new skills and gain confidence. Moreover, being active at a young age is a predictor of being active when the child grows older (Findlay et al., 2009; Ridgway et al., 2009). The importance of children being active and involved in different types of play and activities from an early age may not always be obvious to parents of children with a physical disability. The children with a physical disability included in this study were all going to therapeutic toddler groups or schools for special education. Some parents of children with disabilities may consider their child to be vulnerable and perhaps let their child engage in fewer activities because these views (Bartlett, Nijhuis-van der Sanden, Fallang, Fanning, & Doralp, 2011). Through completion of the APCP, parents can become more aware of all the activities their child is doing or could very well be doing (adapted to the abilities of the child if necessary). The parents' awareness of their children's current and potential opportunities to participate could be the first step to helping families find ways to increase skills or activities or community resources to support their children's engagement in a variety of activities. This makes the Dutch APCP a very valuable tool for rehabilitation professionals aiming to improve participation of preschool children and involving parents in this process.

Participation in leisure activities is influenced by a range of factors in the environment for both children with and without a physical disability. Data about the environment of the child and its relationship to participation were not available for this article. For future research it would be very interesting to get a comprehensive view of the day-to-day living situation of the child. Not only the physical environment, but also the social environment of the child is important. Since participation of preschool children occurs within a family context, family related variables (e.g. family income, activity level of the family) are of great importance. Many variables have been shown to be associated with participation of school-aged children with physical disabilities in quantitative studies, but they explain little of the total variance for participation in leisure activities and extensive statistical analysis are needed to disentangle direct and indirect effects of these variables on participation (Imms et al., 2009; King et al., 2006). Because measurement of environmental factors is difficult, qualitative interviews with parents and children could help to determine the environmental variables that are important to participation of children and families.

In summary, this study has shown the Dutch APCP to be a valid and reliable measure of participation in children 2 to 5 years and 11 months. Future research should ideally focus on the interrelationships between child, family and environmental factors not included in the current study, but which may possibly be associated with preschool children's participation.

Conclusion

The Dutch APCP is an instrument that measures participation of preschool children in a direct, reliable and valid way. It is a relatively quick, simple and cheap instrument to measure preschool children's participation and is therefore very suitable for use in research and in clinical practice for children without and with a physical disability in the Netherlands.

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Chapter 3

Cross-cultural validation and psychometric evaluation of the Dutch language version of the Children's Assessment of Participation and Enjoyment (CAPE) in children with and without physical disabilities

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ABSTRACT

Objective: To assess construct validity, test-retest reliability and inter-interviewer reliability of the intensity dimension of the Children's Assessment of Participation and Enjoyment (CAPE) for children with and without physical disabilities in the Netherlands.

Subjects: In total 232 children aged 6-8 years (110 male, 122 female) participated. Seventy-four children with various physical disabilities and 158 without a disability.

Design: Participants completed the CAPE and the Peabody Picture Vocabulary Test. In addition, parents of 142 children were interviewed using the Vineland Adaptive Behavior Scales and the Family Environment Scale. For 71 children test-retest reliability and for 60 children inter-interviewer reliability were assessed. Validity was examined by assessing differences in participation intensity in children with disabilities versus without a physical disability, boys versus girls, and younger versus older children. In addition, 13 hypothesis regarding participation, child and family variables were examined.

Results: Validity of the CAPE was supported by significant differences in participation for subgroups. Participation differed significantly in children with and without disabilities. Girls participated more in all activities. Older children participated more in social activities and self-improvement activities, younger children participated more in recreational activities. Validity of the CAPE was further supported with significant correlation coefficients in 8 out of 13 hypotheses. Both test-retest and inter-interviewer reliability were good to excellent.

Conclusions: The findings indicate that the Dutch language version of the CAPE is a reliable and valid instrument to measure participation in recreation and leisure activities for children with and without physical disabilities aged 6-18 years.

INTRODUCTION

In the last decade participation has become increasingly important in describing human functioning of children and adults with health conditions. Participation is defined as 'involvement in life situations' (WHO, 2001) and is one of the central concepts in the International Classification of Functioning (ICF) and the recently published ICF version for Children and Youth (ICF-CY; WHO, 2004).

For children, becoming involved in life situations and interacting with others is a crucial element in their development. Participating allows them to develop skills and competencies and form friendships and relationships (King et al., 2003). Although children with physical disabilities participate in a variety of activities they do so with a lower frequency than children without physical disabilities (Imms, Reilly, Carlin, & Dodd, 2008; Majnemer et al., 2008). The activities they undertake are more often home based instead of community based and they participate more with family members instead of friends (Imms et al., 2008). Children with a more severe physical

disability are more restricted in their participation but for the activities they undertake they report a high level of enjoyment (Imms et al., 2008; Majenemer et al., 2008; McManus et al., 2008).

It is not only a child's physical abilities that are associated with participation. Participation is interrelated with a range of other factors within the child (personal factors) and the environment (such as attitudes, support and relationships, national policies). Age, gender, family activity preferences and family income are found to be associated with participation (King et al., 2007; Shikako-Thomas, Majnemer, Law, & Lach, 2008). Participation thus interrelates with many factors and the place where you live has a strong influence, so measuring participation in different countries is important.

In the research literature, participation is assessed either with or without the use of standardized measures. Most measures were not specifically designed to measure participation and measure only a part of participation as defined in the ICF-CY (Sakzewski, Boyd, & Ziviani, 2007). The Children's Assessment of Participation and Enjoyment (CAPE) is an example of a measure designed to assess participation in recreation and leisure activities outside mandated school hours for children with and without disabilities from 6 to 21 years of age King et al., 2007; King et al., 2004). The CAPE has been well validated with a large group of children with different diagnoses in Canada and is regarded highly useful for practice and research (Imms, 2008).

The CAPE has been used for research purposes in different countries, but the validity and reliability have only been studied once using an adapted Spanish version (Colon, Rodriguez, Ito, & Reed, 2008). The validity and reliability in Israel was reported in an unpublished work (Engel-Yeger & Jarus, 2008). Other studies in Australia and the United State have not assessed validity and reliability for the CAPE in their countries (Imms et al., 2008; Hilton, Crouch, & Israel, 2008). Since the place where you live may have a large influence on participation, it is important to examine the psychometric qualities of the CAPE in different countries. Moreover, if the ICF is to be a common language for classifying human functioning there is a need to measure concepts of the ICF in a more global way (Simeonsson, 2003). Using the same, well validated measures will contribute to our understanding of differences in participation between countries.

The CAPE is a child self-report measure of participation in recreation and leisure activities. It examines diversity (which activities does the child do), intensity (how often does a child do activities) and enjoyment (how much does the child enjoy the activity) of participation. The CAPE also asks with whom and where activities are undertaken. The construct validity of the CAPE has been tested with a group of 427 children with various physical disabilities aged 6 to 15 years (King et al., 2004; King et al., 2007). Small to moderate correlation coefficients were found between CAPE intensity scores and environmental, family and child factors supporting

the construct validity of the CAPE. Moreover, test-retest reliability was evaluated and supported in a group of 48 children with various physical disabilities.

Although the CAPE was designed for use for children with and without a disability, validity and reliability have only been studied and confirmed for children with physical disabilities. If the CAPE is a valid instrument for children with and without disabilities, assessing both groups should result in the same psychometric properties as found in the original study focussing only on children with disabilities. Furthermore, reliability of the CAPE has only been examined for test-retest assessments. However, since assessment by different assessors could influence scores, inter-interviewer reliability is an equally important, yet unexplored, issue in the CAPE.

Using an existing instrument to measure participation presents the challenge of finding a balance between keeping essential features of the instrument and adapting it to a specific culture. This requires a process of translating and cross-cultural adaptation according to predefined guidelines. This process should result in an equivalent scale suitable in another culture (Chawlow, 1995). Equivalence can be achieved focusing on different characteristics of a measure. Herdman (1998) describe six types of equivalence including 'measurement equivalence'. They defined measurement equivalence as: "The extent to which the psychometric properties of different language versions of the same instrument are similar" (p. 330). If a study aims for measurement equivalence the intention is not to alter a measure for the purpose of improving psychometric properties; it only translates and adapts the measure for use in a specific culture and allows comparison of results found in different cultures.

The aim of the present study was to assess construct validity, test-retest reliability and inter-interviewer reliability of the intensity dimension of the CAPE for both children with and without physical disabilities in the Netherlands. With regard to construct validity, the following hypothesis was formulated: children with physical disabilities have lower participation intensity scores than children without physical disabilities on the five activity types (recreational, active physical, social, skill-based and self-improvement activities) of the CAPE.

To further examine the construct validity the hypotheses of the original study were used (King et al., 2007). The original study hypothesized that several child, family and environmental factors were related to activity types of the CAPE. In the present study the basic assumption was made that the significant relations, that supported the validity of the original version, would also support the validity of the Dutch language version of the CAPE. Therefore hypotheses regarding the relation between participation intensity and several child variables (gender and age of the child, cognitive, communicative, physical and social functioning) and several family variables (recreational and intellectual cultural orientation) were examined.

METHODS

A convenience sample of children with and without physical disabilities was taken from two schools for special education for children with physical disabilities, and from five regular schools in the Netherlands, respectively. Moreover, a broad call to participate was posted in the social environment of the researchers and among employees of a large rehabilitation centre. Children were eligible if they were aged between 6 and 18 years and were able to complete the CAPE with or without assistance. After approval of the ethics committee of University Medical Center Utrecht and the local school management, parents were sent an information letter about the study, together with a consent form and a stamped return envelope. People who returned the informed consent form participated in the study.

In total 232 children aged 6 to 18 years (110 male, 122 female) participated in the study. Seventy-four children attended schools for special education for children with physical disabilities (mean age =12.0 years; SD = 3.4) and 158 children attended regular schools (mean age = 10.9 years; SD = 3.1). Group characteristics are shown in Table 3.1.

Table 3.1 Group characteristics of the validation study

	Study sample *N* = 232		Children with a physical disability *N* = 74		Children without a physical disability *N* = 158	
	n	%	*n*	%	*n*	%
Gender						
Female	122	52.6	36	48.6	86	54.4
Male	110	47.4	38	51.4	72	45.6
Age (in years)						
6-12	126	54.3	34	46.0	92	58.2
Boys	61		18		43	
Girls	65		16		49	
13-18	106	45.7	40	54.0	66	41.8
Boys	49		20		29	
Girls	57		20		37	
Diagnoses						
Cerebral palsy			28	37.8		
Spina bifida			5	6.8		
Arthritis			6	8.1		
Other			35	47.3		

Several measures were included in the assessment to test the hypotheses in this study. The CAPE and the Peabody Picture Vocabulary Test (Dunn & Dunn, 2005) were completed by the participants. Parents of the children were interviewed using the Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984) and the Family Environment Scale (Moos & Moos, 1994).

Participation

The CAPE consists of 55 items measuring five dimensions of participation: 1) diversity: 'Have you done this activity in the past four months?' (indicating 'yes' or 'no'); 2) intensity: 'How often?' (Likert item ranging from 1; 1 time in the past four months -7; 1 time a day or more); 3) with whom: 'With whom do you do this most often?'; 4) where: 'Where do you do this most often?' and 5) enjoyment: 'How much do you like or enjoy doing this activity?' Each of these questions is put to the child in relation to five activity types: 1) recreational (12 items), active physical (13 items), social (10 items), skill-based (10 items) and self-improvement activities (10 items). For each activity type a score can be obtained as well as an overall participation score and a score for formal and informal activities. The formal domain consists of 15 items and the informal of 40 items. Validity was supported by small to moderate correlations found between scores on the CAPE and several child, family and environmental factors 7. For test-retest reliability correlation coefficients ranged between 0.72 and 0.81 (King et al., 2007).

In this study the intensity of the five activity types was studied. Higher scores indicate more participation. First, the original CAPE was translated from English into Dutch. Following this, expert opinion was obtained from a group of nine independent professionals consisting of occupational therapists, physical therapists, and researchers all working in the field of child rehabilitation. According to the experts none of the items of the CAPE had to be replaced or deleted and therefore all original items were retained. Based on feedback of the professionals however, some activities in the CAPE were explained in more detail and/or examples were added. English text in the pictures was translated. After processing these changes, the items were translated back into English by a native speaker. The original content of the questionnaire was checked and approved by the authors of the CAPE.

Cognition

The Peabody Picture Vocabulary Test (Dunn & Dunn, 2005) is a measure of receptive vocabulary for children and adults. In this test words are verbally presented and out of four presented pictures one has to be selected that matches the verbally presented word. The scores

of this test are presented in a composite score (mean = 100; SD = 15). There is evidence for validity and reliability of the test. The composite score highly correlates with a score on a global cognitive measure (.83 with Wechsler Preschool and Primary Scale of Intelligence). Correlation coefficients for test-retest reliability ranged between 0.92 and 0.97 for children between 6 and 18 years of age (Dunn & Dunn, 2005).

Communicative, social and motor skills

The Vineland Adaptive Behavior Scales is a measure of adaptive behaviour (Sparrow et al., 1984). In a semi-structured interview parents are asked about their child's behaviour. They can indicate whether their child does a certain activity or has certain skills by indicating 'usually' (2 points), 'sometimes' (1 point) or 'never' (0 points). In this study the survey version was used to assess functioning on three scales; social skills, communicative skills and physical skills. The Psychometric qualities of the Vineland Adaptive Behavior Scales are excellent. The correlation coefficients range from 0.95-0.99 and from 0.93-0.99 for test-retest reliability and inter-interviewer reliability, respectively (Sparrow et al., 1984).

Family variables

The Family Environment Scale (Moos & Moos, 1994) is a measure of each family member's perceptions of the family. The measure consists of ten subscales. In each scale family members indicate if the statement describes their family by answering 'yes' or does not describe their family by answering 'no'. In this study the subscales 'Active recreational orientation' and 'Intellectual cultural orientation' were completed by one of the parents of the child. Active recreational orientation measures the amount of participation in social and recreational activities of the family. Intellectual cultural orientation measures the level of interest in political, intellectual and cultural activities of the family. Correlation coefficients for internal consistency and test-retest reliability range from 0.61 to 0.78 and from 0.52 to 0.91, respectively (Moos & Moos, 1994).

Procedure

Data were collected by 12 research assistants, who received a training in administration of the measures. The CAPE was completed in a one-on-one session with one of the research assistants. All measures for one child were administered by the same research assistant. In almost all cases the research assistant also interviewed the parent of the same child. Participants were seen at school during classes or at home. The CAPE and the Peabody Picture Vocabulary Test were

completed by 185 participants. Parents of 142 children were interviewed using the Vineland Adaptive Behavior Scales and the Family Environment Scale. A group of 71 children completed the CAPE again with the same interviewer after four weeks to assess test-retest reliability. A group of 60 different children completed the CAPE again after one week with a different interviewer to assess inter-interviewer reliability. Children with and without physical disabilities were included in both the test-retest reliability and the inter-interviewer reliability assessment

Statistical analyses

Mean intensity scores for each of the five activity types were calculated if at least 80% of the items in the activity type were completed (King et al., 2004). Calculated intensity scores could range from 0 to 7. Zero was scored if the child did not do the activity. This resulted in a score 0 on the diversity question and the intensity question. If the child did do the activity then the diversity score 1 was multiplied with the score on the intensity question ranging from 1 to 7. Differences between groups were analysed using *t*-test for independent samples (according to the original study the level of statistical significance was set at .05 two tailed). Pearson product moment correlations were calculated to analyse relations between intensity scores of the CAPE and scores on relevant other measures as described above (according to the original study the alpha was set at .01 two-tailed to control for type I error). Test-retest reliability and inter-interviewer reliability was analysed by correlating intensity scores from the first and second assessment with intraclass correlation coefficients (ICC two-way mixed). To determine whether a measurement instrument can be considered reliable a commonly used ranking was followed. ICC values of > 0.75 are excellent, from 0.60 to 0.74 are good, from 0.40 to 0.59 are moderate, and values less than 0.40 are poor (Fleis, 1981). In order to assess the amount of error associated with repeated measurements, the Standard Error of Measurement (SEM) was calculated by taking the square root of the error variance (de Vet, Terwee, Knol, & Bouter, 2006). The Smallest Detectable Change (SDC) was derived from the SEM, according to SDC = 1.96 x $\sqrt{2}$ x SEM (de Vet et al., 2006). The SDC is the smallest difference in measurement that can be interpreted as a real difference between two measurements in an individual.

RESULTS

The CAPE was completed by 232 children, the Peabody Picture Vocabulary Test (Dunn & Dunn, 2005) was completed by 185 participants. Parents of the children were interviewed using the Vineland Adaptive Behavior Scales (Sparrow et al., 1984) and the Family Environment Scale (Moos & Moos, 1994). A total of 142 parents completed both measures.

Mean intensity scores for children with and without physical disabilities are presented in Table 3.2. Children with physical disabilities participated with a lower intensity in all activities except recreational activities, compared to their non-disabled peers.

Girls participated significantly more in all activities except active physical activities compared to boys (Table 3.3). Older children participated more in self-improvement activities and social activities whereas younger children participate more in recreational activities (Table 3.4). Pearson correlation coefficients for the hypotheses on the relationship between intensity of participation and other child and family variables were small to moderate and 8 out of 13 hypothesized coefficients reached statistical significance. In general the magnitude of the correlation coefficients was comparable to those reported in the Canadian study. Correlation coefficients are presented in Table 3.5.

Table 3.2 Mean intensity scores (standard deviation) for children with and without physical disabilities

	Children with a physical disability Mean intensity scores (range 0-7) *N* = 74	Children without disability Mean intensity scores (range 0-7) *N* = 158	*t*-value
Recreational activities	3.21 (1.26)	3.38 (1.13)	1.01
Active physical activities	1.05 (0.69)	1.58 (0.74)	5.18**
Social activities	2.40 (1.01)	2.85 (0.99)	3.20*
Skill-based activities	0.85 (0.84)	1.13 (0.80)	2.47*
Self-improvement activities	1.72 (0.97)	2.36 (1.07)	4.40**

* $p < 0.05$, ** $p < 0.01$

Table 3.3 Mean intensity scores (standard deviation) for boys and girls

	Boys Mean intensity scores (range 0-7) *N* = 110	Girls Mean intensity scores (range 0-7) *N* = 122	*t*-value
Recreational activities	3.16 (1.16)	3.47 (1.17)	-2.03*
Active physical activities	1.67 (0.76)	1.17 (0.68)	5.32**
Social activities	2.48 (1.00)	2.91 (0.99)	-3.35**
Skill-based activities	0.69 (0.61)	1.36 (0.86)	-6.87**
Self-improvement activities	1.87 (0.94)	2.41 (1.14)	-3.98**

* $p < 0.05$, ** $p < 0.01$

Table 3.4 Mean intensity scores (standard deviation) for younger and older children

	Children aged 6-11 years Mean intensity scores (range 0-7) *N* = 126	Children aged 12 -18 years Mean intensity scores (range 0-7) *N* = 106	*t*-value
Recreational activities	3.84 (1.05)	2.71 (0.99)	8.36**
Active physical activities	1.32 (0.75)	1.51 (0.77)	-1.85
Social activities	2.31 (0.93)	3.17 (0.93)	-7.03**
Skill-based activities	0.96 (0.75)	1.14 (0.89)	-1.70
Self-improvement activities	1.96 (1.04)	2.34 (1.10)	3.08*

* $p < 0.05$, ** $p < 0.01$

Table 3.5 Hypotheses and correlation coefficients between CAPE intensity scores and other variables

Hypothesis	Correlation coefficient (*r*)
Recreational activities are positively associated with the family's active recreational orientation (FES)	0.04
Active physical activities are positively associated with the child's physical functioning (VABS).	0.31*
Active physical activities are positively associated with the family's active recreational orientation (FES).	0.34*
Social activities are positively associated with the child's communicative functioning (VABS).	0.39*
Social activities are positively associated with the child's social functioning (VABS).	0.38*
Social activities are positively associated with the child's physical functioning (VABS).	0.17
Social activities are positively associated with the family's active recreational orientation (FES).	0.02
Skill based activities are positively associated with the family's intellectual cultural orientation (FES).	0.26*
Skill based activities are positively associated with the family's active recreational orientation (FES).	0.08
Self-improvement activities are positively associated with the child's communicative functioning (VABS).	0.51*
Self-improvement activities are positively associated with the family's intellectual cultural orientation (FES).	0.28*
Self-improvement activities are positively associated with the child's cognitive functioning (PPVT-III)	0.24*
Self-improvement activities are positively associated with the family's active recreational orientation (FES).	0.10

FES, Family Environment Scale; VABS, Vineland Adaptive Behavior Scales; PPVT-III, Peabody Picture Vocabulary Test. Correlation coefficients of relations with the FES and the VABS are based on *N* = 142. Correlation coefficients of relations with the PPVT-III are based on *N* = 185.
* $p < 0.01$

The mean time between the first and second assessment for the inter-interviewer reliability was 8 days (SD = 2). The mean time between the assessments for test-retest reliability was 31 days (SD = 6). ICCs for inter-interviewer reliability and for test-retest reliability are presented in Table 3.6. To illustrate the distribution of scores, the data of the inter-interviewer reliability for the recreational activities are presented in Figure 3.1. This is just one example of the activity types. ICCs for inter-interviewer reliability were good to excellent with ICCs ranging between 0.65 and 0.83. For the test-retest reliability correlation coefficients were also good to excellent and ranged between 0.61 and 0.78. The correlations found in this study are comparable to the ones in the original study. The SDCs ranged between 0.89 and 1.91 for the inter-interviewer reliability and between 1.14 and 1.86 for the test-retest reliability.

Table 3.6 Data on reliability for CAPE intensity scores

	Inter-interviewer (*n* = 60)				Test-retest (*n* = 71)			
	ICC	95% confidence interval ICC	SEM	SDC	ICC	95% confidence interval ICC	SEM	SDC
Recreational activities	0.75	(0.62-0.84)	0.60	1.66	0.71	(0.58-0.81)	0.57	1.58
Physical activities	0.66	(0.48-0.78)	0.45	1.25	0.68	(0.53-0.79)	0.41	1.14
Social activities	0.65	(0.48-0.78)	0.69	1.91	0.61	(0.44-0.74)	0.67	1.86
Skill based activities	0.83	(0.73-0.90)	0.32	0.89	0.78	(0.66-0.85)	0.42	1.16
Self improvement Activities	0.72	(0.58-0.83)	0.61	1.69	0.72	(0.58-0.81)	0.62	1.72

ICC, intraclass correlation coefficient; SEM, standard error of measurement; SDC, smallest detectable change. SEMs and SDCs are expressed in the units of the measurement scale (0-7).

DISCUSSION

The findings of the study indicate that the Dutch language version of the CAPE is a valid and reliable instrument to measure participation intensity in activities outside school for children with and without physical disabilities aged 6 to 18 years in the Netherlands.

To our knowledge, this is the first study in which participation of children with and without physical disabilities was compared using the CAPE. Only the study by Colon et al. (2008) included Spanish children with and without physical disabilities but these authors used an altered version of the original CAPE. Imms et al. (2008) have used the original CAPE and a government database as a reference to compare participation in Australian children with

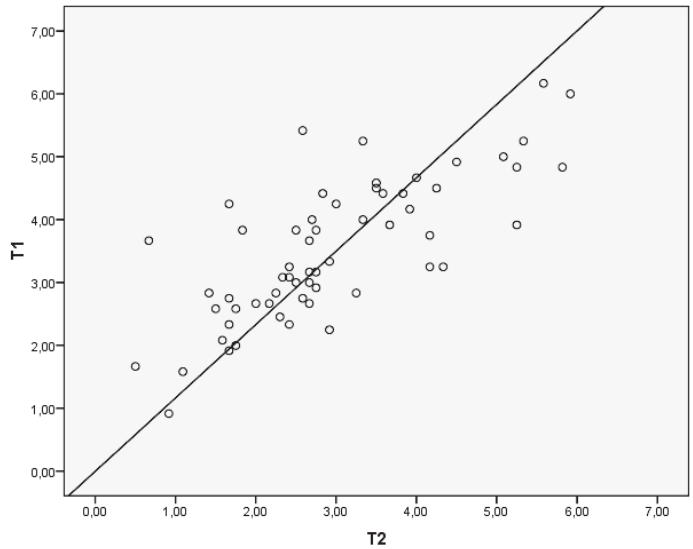

Figure 3.1 Scatterplot inter-interviewer reliability (recreational activities). T1 = first assessment, T2 = second assessment.

and without physical disabilities. By including both groups and using the same instrument the current study was able to show that children with physical disabilities in the Netherlands participate less frequent in almost all activities than children without physical disabilities. This finding is in line with previous literature on participation of children with physical disabilities (Imms et al., 2008; Majnemer et al., 2008; Shikako-Thomas et al., 2008).

In the current study validity was supported by testing confirmed hypotheses from the original Canadian study. Notable is that the hypotheses that could not be confirmed were almost all in relation to the active recreational scale of the Family Environment Scale. In the Netherlands, a Dutch (adapted) version of the Family Environment Scale is available. However, since this version does not contain the active recreational and intellectual cultural orientation scales, which would have been necessary to compare our data with the Canadian data, we have chosen to use a direct translation of the Family Environment Scale. Since we have no information on the reliability of this translated Family Environment Scale, interpretation of the correlations should be made with caution.

The inter-interviewer and the test-retest reliability coefficients for intensity found in this study were good to excellent. Children reported the intensity of participation in activities themselves. Especially for younger children, four months is a long period of time. Although research shows that even young children do have a good idea about time when it is put in a meaningful context

(Hoodless, 2002) one could imagine that reporting how often an activity is done is less accurate and could influence reliability coefficients. Moreover this study does not provide information about children with more complex disabilities including more severe communicative and cognitive problems. Future research should consider possibilities to include these children as well to get more insight in their activities. Although the assessment time can be shortened by letting parents partially complete the questionnaire, children will always have to report the enjoyment of and the preferences for activities themselves. Future research could assist in finding variables that influence the accuracy of reporting activities over the past four months and could focus on the difference in the completed questionnaires by parents and children.

The data show relatively low scores on the skill-based activities. These activities include different kind of classes and participation in community organizations. This is apparent in both children with and without disabilities, boys and girls and in different age groups. In other international studies that used the CAPE low participation in skill-based activities is also seen (Imms et al., 2008; Orlin et al., 2009).

The reliability coefficients were good to excellent. The smallest detectable change is relatively large (ranging from 0.89 to 1.91 on a scale from 0 to 7). This means that an individual must show substantial change in scores to detect a 'real' change. Interpretation of change in individual cases must therefore be done with caution.

This study has shown that children with physical disabilities participate less in almost all activities. The factors that lead to lower participation should be identified at group as well as individual level. Identifying these factors is a complex task and may not lead to a conclusive model of factors. Morris (2009) described the capability approach for measuring participation. In this approach a distinction is made between capacity (being able to perform an activity in an ideal environment), capability (being able to perform an activity in one's own environment) and performance (achieved functioning). Most measures of participation only focus on performance. However, whether a child that has the capability to do something will get to performance is also dependent on individual choices. So, measuring performance of participation should not determine if a child does well in life or not (Hammel et al., 2008). Individual choices should be incorporated in a model of factors related to participation. The individual preferences can be assessed by the Preferences for Activities of Children (PAC)(King et al., 2004). More insight into the preferences of children can provide valuable information on participation. Research about participation should ideally be accompanied by information about preferences. In clinical settings these preferences could guide intervention planning. Intervention based on goals set by children and families are known to be more effective than conventional interventions (Ketelaar, Vermeer, Hart, van Petegem, & Helders, 2001; Østensjø, Oien, & Fallang, 2008;

Eccles & Wigfield, 2002). The PAC could be used to increase effectiveness of, and motivation for intervention.

The CAPE measures participation in children age 6-18 years. Participation in all kinds of activities does not start at age six. Before the age of six children participate together with their families (McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006). From recent research it is known that families with a young child with a physical disability perceive their participation as restricted (Rentinck, Gorter, Ketelaar, Lindeman, & Jongmans, 2009) and they participate more in informal than formal activities (Mactavish, Schleien, & Tabourne, 1997). Monitoring participation at an early age and offering intervention if needed could possibly enhance later participation. The Pre-school CAPE (King, Law, Forhan, Hurley, & Kertoy, 2004) is a measure designed to assess participation in children aged two to six years. Future research should assess validity and reliability of this measure.

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Chapter 4

What influences participation in leisure activities of children and youth with physical disabilities? A systematic review

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ABSTRACT

In 2001 the International Classification of Functioning (ICF) defined participation as 'someone's involvement in life situations'. Participation in leisure activities contributes to the development of children and their quality of life. Children with physical disabilities are known to be at risk for participation in fewer activities. The group of children with physical disabilities is highly heterogeneous consisting of children with different diagnosis and different ages. This systematic review aims to analyse the literature for the purpose of looking for variables involved in the frequency of participation in leisure activities for children and youth with different diagnoses and ages. Frequency of participation in leisure activities for children and youth with physical disabilities is associated with a variety of variables. Gross motor function, manual ability, cognitive ability, communicative skills, age and gender are the most important variables. The current evidence suggests that similar variables seem to apply to children with different diagnoses. Age is an important variable in participation of children and youth. However evidence about those variables associated with children at different ages is still lacking.

INTRODUCTION

In 2001, the World Health Organization published the International Classification of Functioning disability and health (ICF) (WHO, 2001). The major goal of the ICF is to describe aspects of human functioning that are related to health status in a standardized way to provide a basis for a common language (WHO, 2001). In 2004, this classification was followed by the children and youth version, the ICF-CY (WHO, 2004). The ICF-CY also provides a common language but focuses on the relation between health status and changes that emerge in development from infancy to adolescence. When looking at determinants, the common language proposed by the ICF-CY is thought to be helpful in providing insight into which variables are related to participation (Björck-Åkesson et al., 2010). This common language could help to describe determinants in a unified way.

The ICF-CY uses three levels (each consisting of one or more domains) to classify human functioning: (1) health condition, (2) body structure and functions, activities and participation, and (3) environmental and personal factors. Each domain is divided in chapters that can be used to code human functioning. Activities are defined as 'the execution of specific tasks or actions by an individual'. Participation is defined as 'someone's involvement in life situations' (WHO, 2004).

The activity and participation domain consists of several chapters including the chapter 'Community, social and civic life' in which participation in leisure activities is operationalized as consisting of play, sports, culture, crafts, hobbies and social activities.

Leisure activities for children are regarded as 'the time designated for freely chosen activities, performed when not involved in self-care or work or school'. More specifically, leisure activities are defined as 'everyday activities of childhood in all sport, entertainment, learning and religious expression' (King et al., 2003; Majnemer, 2009). Being active and involved in freely chosen activities is essential for the development of skill competencies, socializing with peers, exploring personal interests and enjoying life (Simpkins, Ripke, Huston, & Eccles, 2005). Without opportunities to participate in leisure activities "people are unable to explore their social, intellectual, emotional, communicative and physical potential and are less able to grow as individuals" (King et al., 2003). Moreover, participation contributes to the quality of life for children and youth (Mc Manus, Corcoran, & Perry, 2008). Children and youth with physical disabilities participate less in leisure activities than their able bodied peers (Bult et al., 2010; Engel-Yeger, Jarus, Anaby, & Law, 2009; Imms, Reilly, Carlin, & Dodd, 2008). Moreover, their leisure activities tend to be more home-based and organized by adults (Majnemer et al., 2008; Shikako-Thomas, Majnemer, Law, & Lach, 2008). In conclusion, leisure activities are essential for the development of all children, particularly for children who are disabled.

Most children with a physical disability are involved in rehabilitation services from an early age. One of the primary goals of rehabilitation is 'to improve and optimize daily functioning, engagement in life and well being' (Gorter, 2009). Recent research has shown that parents, youth and professionals consider enhanced participation in leisure activities as one of the most important outcomes of intervention (Vargus-Adams & Martin, 2010). Therefore, it is important to know what variables are related to participation in leisure activities.

Recent reviews (Imms, 2008; Shikako-Thomas et al., 2008), focussing on participation in leisure activities of children with cerebral palsy (CP), show that several child, family and environmental factors influence participation. Looking at child-related factors, it appears that children older than twelve years of age and children having poorer motor function participate less than their peers. Gender and preference influence the choice for specific activities. Lower family income and a lower parental education level are associated with lower participation levels in children. Lower levels of stress within the family and better family coping may be important facilitators of participation. Environmental factors including lack of equipment, information and peer support, and dependence on adults also limit children's full participation in leisure activities.

In the Netherlands, almost all rehabilitation centers provide specialised child rehabilitation services that focus on all age groups from infancy up until adolescence (Faber, Mulders, & Van Tol-de Jager, 2008). Two-thirds of the paediatric population receiving rehabilitation care has a physical disability caused by neurological problems and one-third of the population has a disability due to other causes (Faber et al., 2008). Both groups are highly heterogeneous

consisting of numerous diagnoses and each group experiences different problems in daily life. Children and youth with CP represent the largest group in paediatric rehabilitation (Yeargin-Allsopp et al., 2008).

It is important for rehabilitation specialists to know if variables that impose a risk to optimal participation in leisure activities for children and youth with CP are similar or dissimilar to the risk factors for participation by children with other diagnoses. This will help to provide optimal rehabilitation care for the varied populations needing rehabilitation services. Moreover, since child rehabilitation services are aimed at children and youth of all ages it is important for rehabilitation professionals to know which factors are related to optimal participation in each developmental stage in order to provide effective interventions. It is likely that a toddler undertakes different activities than an adolescent and therefore has other needs for optimizing age appropriate participation in leisure activities. However, such knowledge is currently still lacking.

The purpose of this review is to systematically analyse the literature in order to identify variables involved in the frequency of participation in leisure activities for children and youth with various diagnoses of physical ability. Our questions are: (1) Can different variables be identified for different diagnostic groups? and (2) Can different variables be identified for different age groups?

METHODS

Search

A comprehensive search was performed using the PubMed, Medline, Embase, Psychinfo and Cinahl databases. The databases were searched from January 2001 (presentation of the ICF) until January 2010.

Search terms used were aimed at identifying children aged 2-18 years. They included 'preschooler(s)', 'preschool child(ren)' and 'toddler(s)' to identify children aged 2-5 years of age. Search terms 'child' or 'children' were used to identify children aged 6-12 years. To identify youth aged 12-18 years the terms 'adolescent(s)', 'adolescence', 'youth' and 'teenager(s)' were entered. These search terms were combined with 'participation' AND ('leisure' OR 'recreation' OR 'activity' OR 'activities').

To ensure that no diagnosis of physical disability would be missed beforehand, no definition of diagnoses was used in the search terms. Exclusion criteria were: (1) studies provided no

objective to describe determinants of participation, (2) studies were limited to children under the age of two or youth above the age of 18 years, (3) studies only aimed at comparing children with and without physical disabilities, (4) intervention studies, (5) studies published in other than the English language, (6) review papers, (7) studies aimed at validating measures, (8) qualitative studies (the results of these studies were hard to compare with the quantitative studies), and (9) studies focusing on children and youth with acquired brain injury (ABI). These latter studies were excluded because the population of children with ABI is highly heterogeneous. Time of onset of the injury, and therefore course of development, causes large differences between the children and makes the results difficult to compare. Moreover, children with ABI are likely to recover from their (temporary) physical constraints although a large group will continue to suffer from cognitive, behavioural and emotional problems (Fay et al., 2009).

Selection of studies

The first author (MB) evaluated all studies and selected studies based on title, abstract and the exclusion criteria mentioned above. After the first selection, the remaining studies were also evaluated by the second author on the basis of their titles and abstracts (OV). This resulted in a list of publications which were then read in full. Finally, the articles read in full were critically evaluated by both authors based on the exclusion criteria. In cases where disagreements ocurred, consensus was reached through discussion. The articles that remained after selection and evaluation processes were selected for data extraction. In the data extraction phase significant relations were categorized according to the ICF chapters.

RESULTS

Search

The search resulted in a total of 3761 studies from the four databases (see Figure 4.1). After excluding studies, that appeared in multiple databases, 2328 studies were evaluated based on title and abstract. Following this first selection and based on the exclusion criteria, 36 studies remained. A further 19 studies were excluded based on the content of their full text, resulting in 17 studies remaining for this review (Table 4.1). Data extraction was done by the first author and checked by the second author. When disagreements occurred, consensus was reached through discussion.

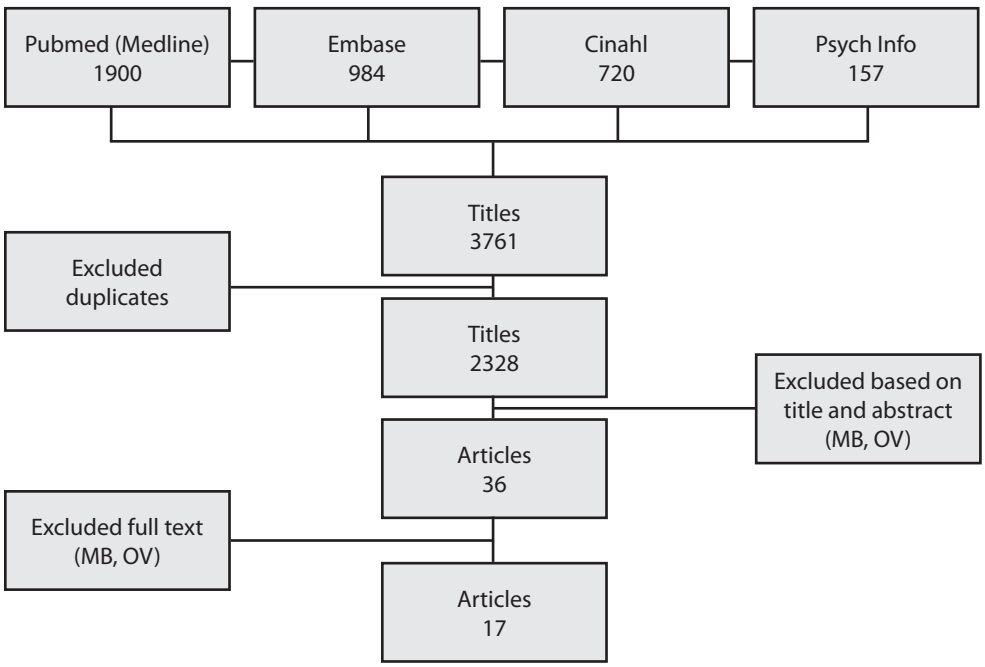

Figure 4.1 Flowchart of study selection.

Data analysis

Participation appeared to be measured in many ways with different measures. It was decided to incorporate subscales of measures that were connected to the domain of 'Community, social and civic life' within the ICF (see Section 1 for a rationale).

General information

Table 4.1 shows the studies included in the analysis that were ranked according to the age of the children (youngest to oldest children). Most studies were about the participation of children with CP (10 studies). Other studies focused on children with spinal cord injury (SCI) (1 study), developmental coordination disorder (DCD) (1 study) and polyarticular arthritis (1 study). Four studies included a combined group including children with disorders related to the central nervous system and children with musculoskeletal disorders.

Table 4.1 Studies included in the review (numbers correspond with numbers in flowchart, Figure 4.2)

Study		Diagnosis	Age group	Participants' age (sd)/range	Participation measure
(1)	Stevenson et al. (2006)	Cerebral palsy	Pre-school, school-aged, adolescent	*N*=273 2-5 years (26%) 6-12 years (39%) 13-19 years (34%)/2-19 years	Interview Questionnaire (adapted from Center of Disease Control and Prevention)
(2)	Kerr et al. (2008)	Cerebral palsy	School-aged, adolescent	*N*=184 USCP *N*=94, M 10.62 (3.49) BSCP *N*=84, M 10.89 (3.70) Non spastic *N*=6, M 11.35 (4.79)/4-17 years	LAQ-CP (Lifestyle Assessment Questionnaire-Cerebral Palsy)
(3)	Beckung & Hagberg (2002)	Cerebral palsy	School-aged	*N*=176 Md 6 years, 6 months/5-8 years	ICIDH codes (5 point scale)
(4)	Morris et al. (2006)	Cerebral palsy	School-aged	*N*=129 M 9 years, 9 months (1 year, 9 months) 6-12 years	ASK (Activities Scale for Kids) LAQ-CP (Lifestyle Assessment Questionnaire-Cerebral Palsy)
(5)	Kerr et al. (2007)	Cerebral palsy	School-aged, adolescent	*N*=59 M 11.04 (3.49)/6-15 years	LAQ-CP (Lifestyle Assessment Questionnaire-Cerebral Palsy)∞
(6)	Majnemer et al. (2008)	Cerebral palsy	School-aged	*N*=67 M 9 years, 7 months (2 years, 1 months) 6 years, 1 months – 12;11 years	CAPE (Children's Assessment of Participation and Enjoyment)

Table 4.1 continues on next page

Table 4.1 *Continued from previous page*

Study		Diagnosis	Age group	Participants' age (sd)/range	Participation measure
(7)	McManus et al. (2008)	Cerebral palsy	School-aged	CP *N*=98 8-9 years *N*=40 10 years *N*=20 11 years *N*=15 12 years *N*=23 Non CP *N*=448 8-9 years *N*=128 10 years *N*=109 11 years *N*=123 12 years *N*=88/8-12 years	Frequency of participation (FPQ)
(8)	Voorman et al. (2006)	Cerebral palsy	School-aged, adolescent	*N*=110 M 11;3 (20 months) /9-13 years	Pediatric Evaluation of Disability Inventory (PEDI-NL) social function, Vineland Adaptive Behavior Scales (VABS), socialization
(9)	Imms et al. (2009)	Cerebral palsy	School-aged	*N*=108 M 11.7 (0.54)/11-12 years	CAPE (Children's Assessment of Participation and Enjoyment)
(10)	Maher et al. (2007)	Cerebral palsy	School-aged, adolescent	*N*=112 M 13.11 (23 months)/11-17 years	Physical Activity Questionnaire for Adolescents (PAQ-A) Questions regarding screen time
(11)	Poulsen et al. (2007)	Developmental Coordination Disorder	School-aged	DCD group *N*= 60, M 11 years, 7 (9.7)/10-13 years Non-DCD group *N*=113 11 years, 9 (9.3)/10-13 years	Seven day leisure-time diary
(12)	Schanberg et al. (2003)	Polyarticular arthritis	School-aged, adolescent	*N*=41 M 12.3 (2.9)/8-17 years	Daily diaries reporting reduction in social activities (4-point likert scale)

(13)	Klaas et al. (2010)	Spinal Cord Injury	School-aged, adolescent	*N*=194 M 13.2 (3.8)/6-18 years	CAPE (Children's Assessment of Participation and Enjoyment)
(14)	Law et al. (2004)	Disorders related to the central nervous system, and children with a musculoskeletal disorder	School-aged, adolescent	*N*=427 6-8 years *N*=125 9-11 years *N*=176 12-14 years *N*=126 10y (2 years, 4 months)/6-14 years	CAPE (Children's Assessment of Participation and Enjoyment)
(15)	King et al. (2006)	Disorders related to the central nervous system, and children with a musculoskeletal disorder	School-aged, adolescent	*N*=427 10y (SD 2 years, 4 months)/6-14 years	CAPE (Children's Assessment of Participation and Enjoyment)
(16)	Law et al. (2006)	Disorders related to the central nervous system, and children with a musculoskeletal disorder	School-aged, adolescent	*N*=427 6-8 years *N*=125 9-11 years *N*=176 12-14 years *N*=126 10y (2 years, 4 months)/ 6-14 years	CAPE (Children's Assessment of Participation and Enjoyment)
(17)	King et al. (2009)	Disorders related to the central nervous system, and children with a musculoskeletal disorder	School-aged, adolescent	*N*=427 10y (2years, 4months) 6-14 years 6-8 years *N*=125 9-11 years *N*=176 12-14 years *N*=126 10y (2 years, 4 months)/6-14 years	CAPE (Children's Assessment of Participation and Enjoyment)

The studies looked at children in different age groups. One study (Stevenson et al., 2006) included children of pre-school age (2-5 years) although they did not analyze the results separately for this age group. Six studies included only children that were school aged (6-12 years) (Beckung & Hagberg, 2002; Imms, Reilly, Carlin, & Dodd, 2009; Majnemer, 2009; Mc Manus et al., 2008; Morris, Kurinczuk, Fitzpatrick, & Rosenbaum, 2006; Poulsen, Ziviani, & Cuskelly, 2007) and no studies were identified that solely included adolescents (13-18 years). Eleven studies included two or more age groups, all combined school-aged children and adolescents (Kerr, McDowell, & McDonough, 2007; Kerr, Parkes, Stevenson, Cosgrove, & McDowell, 2008; King et al., 2006; King et al., 2009; Klaas, Kelly, Gorzkowski, Homko, & Vogel, 2010; Law et al., 2004; Law et al., 2006; Maher, Williams, Olds, & Lane, 2007; Schanberg, Anthony, Gil, & Maurin, 2003; Stevenson et al., 2006; Voorman et al., 2006).

Results are arranged in five domains according to the ICF-CY model; health condition, body structure and function, activities, personal factors and environmental factors (Figure 4.2).

Key factors across diagnostic groups

Health condition

Six studies focusing on children with CP found that the level of gross motor functioning (classified according to the Gross Motor Function Classification System, GMFCS) was an important variable associated with participation (Beckung & Hagberg, 2002; Imms et al., 2009; Kerr et al., 2008; Maher et al., 2007; Morris et al., 2006; Voorman et al., 2006). More severe gross motor problems in children and youth with CP were associated with greater participation restrictions. Despite comparable group size, age and severity of CP, some studies did not find a strong association between gross motor functioning and participation in spontaneous activities once it was analyzed in a multivariate model. Instead, gender, manual ability, preference for activities, cognitive impairment and epilepsy contributed more to the level of participation of children and youth (Imms et al., 2009; Voorman et al., 2006). Severity of physical disability, the number of limbs that were affected, more severe spasticity or more severe spinal cord injury were also related to frequency of participation (Majnemer et al., 2008; Mc Manus et al. 2008; Morris et al., 2006). Furthermore, manual ability (classified according to the Manual Ability Classification System, MACS) was related to participation in leisure activities in three studies including children and youth with CP (Beckung & Hagberg, 2002; Imms et al., 2009; Morris et al., 2006). Better handling of objects and better fine motor function were associated with greater participation in leisure activities.

For children and youth with DCD and SCI more problems in gross motor functioning was also associated with more participation restrictions (Klaas et al., 2010; Poulsen et al., 2007).

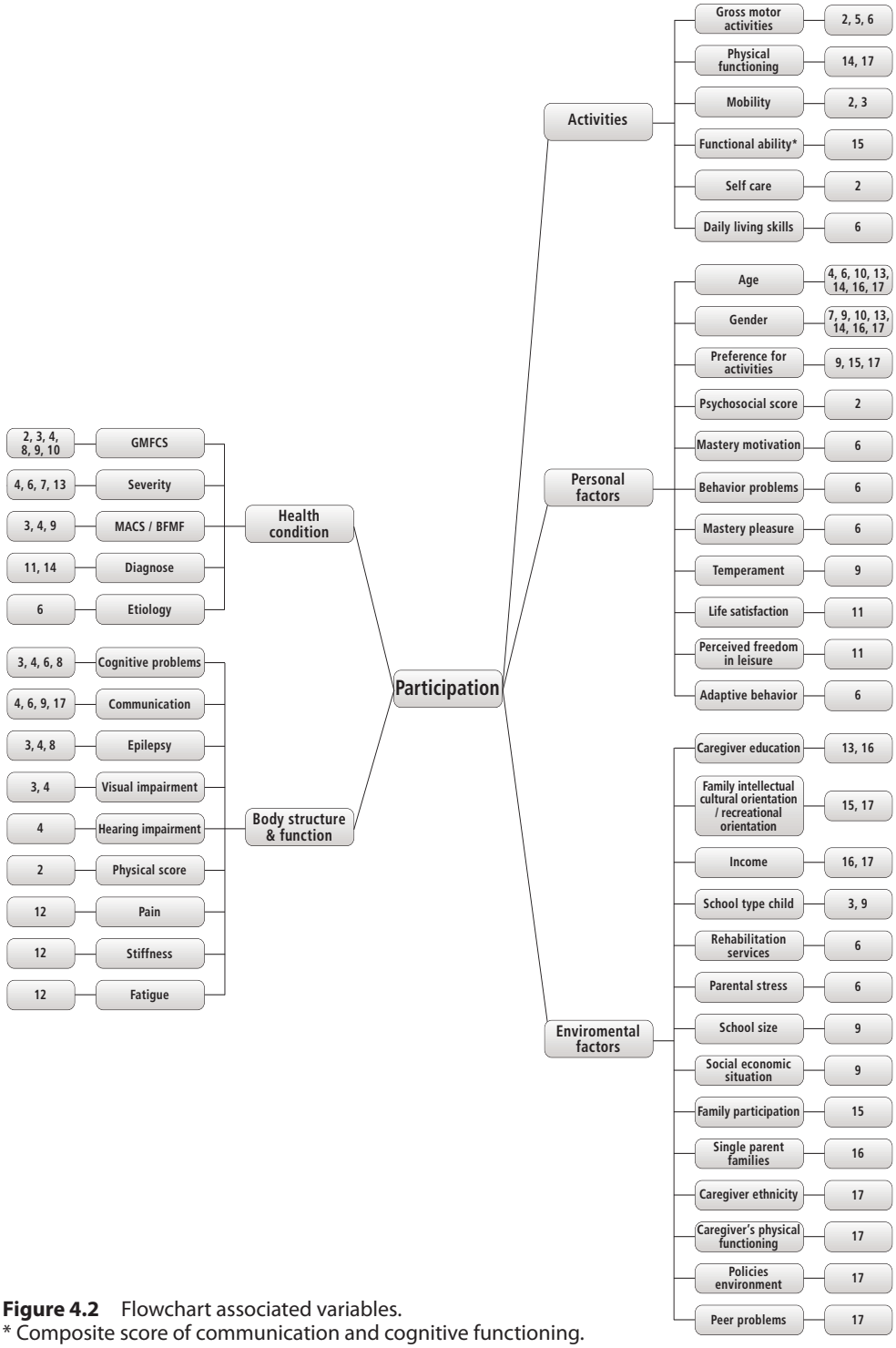

Figure 4.2 Flowchart associated variables.
* Composite score of communication and cognitive functioning.

Children having DCD participated significantly less in both social and physical activities than their non-disabled peers (Poulsen et al., 2007). For children with SCI specifically, spontaneous and non-organized activities were affected by the type of injury Children who are tetraplegic participate less than children who are paraplegic (Klaas et al., 2010).

Body structure and function

Children with CP with co-morbid learning disabilities are at risk for more restricted participation in leisure activities compared to their peers with CP without learning difficulties: the more severe the learning disability, the more likely a child will encounter participation restrictions (Beckung & Hagberg, 2002; Majnemer et al., 2008; Morris et al., 2006; Voorman et al., 2006). King et al. (2006) and McManus et al. (2008) calculated a composite score incorporating intellectual ability and communicative or physical functioning. A lower composite score, meaning lower intellectual ability, was associated with lower participation in spontaneous and organized activities.

Communicative functioning and speech was reported to be another variable associated with participation restrictions in three studies including children with CP and one study including children with different diagnoses (Imms et al., 2009; King et al., 2009; Majnemer et al., 2008; Morris et al., 2006).The results of these studies point to a positive relationship between communication skills and participation in leisure activities. Children with a physical disability and an additional hearing impairment or visual impairment are also at risk for lower levels of participation (Beckung & Hagberg, 2002; Morris et al., 2006).

Three studies have found epilepsy to be related to participation (Beckung & Hagberg, 2002; Morris et al., 2006; Voorman et al., 2006). Children with seizures are at risk for more restricted participation.

In studies looking at children with DCD, polyarticular arthritis and SCI only Schanberg et al.(2003) reported pain, stiffness and fatigue to have a negative influence on participation of children with polyarticular arthritis.

Activities

Being able to perform gross motor activities is important for participation in leisure activities. Better physical functioning in children with CP, as measured at an activity level with the Gross Motor Function Measure (GMFM) and the Activity Scale for Kids (ASK),was associated with higher levels of participation in leisure activities (Kerr et al., 2007; Kerr et al., 2008; King et al., 2006; King et al., 2009; Law et al., 2004; Majnemer et al., 2008). Studies that included children with diagnoses other than CP (DCD, polyarticular arthritis and SCI) did not identify factors at the activity level that influence participation in leisure activities.

Personal factors

Most studies included age and gender in their analyses to explore the potential association of these variables with participation in leisure activities. Both variables contributed significantly to participation level in children with CP as well as children with other diagnoses.

Age is considered to be a significant factor in predicting participation outcome (Law et al., 2004; Majnemer et al., 2008; Morris et al., 2006). Increasing age is related to participation in less activities and less frequent participation (King et al., 2009; Klaas et al., 2010; Law et al., 2006; Maher et al., 2007). Looking at gender effects, girls are found to participate more frequent than boys (Imms et al., 2009; Klaas et al., 2010; Law et al., 2006; Maher et al., 2007; Mc Manus, et al., 2008). Effects of gender are, however, dependent on the type of activities investigated. Girls tend to participate more in social and spontaneous activities and boys participate more in physical activities (King et al., 2009; Law et al., 2006; Maher et al., 2007). Furthermore, the preference for activities, mastery motivation and pleasure in learning new things increases the level of participation in those activities. Children engage in activities they like more often (Imms et al., 2009; King et al., 2006; King et al., 2009; Majnemer et al., 2008).

The relationship of age to participation has also been studied in children with other diagnoses, Klaas et al. (2010) found older children with SCI participated more often socially and in the community than did their younger peers. Poulsen et al. (2007) reported life satisfaction to be positively associated with participation in physical activities in children with DCD.

Environmental factors

Many studies investigated the association between variables in the direct or indirect environment of the child and the level of participation. Family, friends and neighbourhood are examples of the direct environment of the child. Rules, social and cultural aspects, rules and services provided by organizations or the government are considered indirect environment. However, less than half of the studies have actually identified environmental variables to be significantly associated with participation (Beckung & Hagberg, 2002; Imms et al., 2009; King et al., 2006; King et al., 2009; Klaas et al., 2010; Law et al., 2006; Majnemer et al., 2008).

In studies where the child's direct environment was examined, non-Caucasian ethnicity of the parent, lower parental educational level, lower parental physical functioning and higher levels of parental stress were associated with lower participation of the child (King et al., 2009; Klaas et al., 2010; Law et al., 2006; Majnemer et al., 2008). Moreover, family participation in leisure activities and the degree of interest in social and cultural activities were associated with the level of participation of the child: where more interest in these activities results in a higher level of participation for the child (King et al., 2006; King et al., 2009).

In studies that examined the wider environment of the child, going to a mainstream school and attending a larger school were associated with increased participation in activities (Beckung & Hagberg, 2002; Imms et al., 2009). Encountering problems with peers, however, is associated with more restricted participation in social activities (King et al., 2009). Majnemer et al., (2008) have found use of rehabilitation services to be positively associated with the number of different activities children undertake and how often they do these activities. Children that continued to receive rehabilitation services were more likely to participate in activities that require certain skills. In the studies that focused on specific diagnoses, only Klaas et al., (2010) identified environmental factors to be related to participation in leisure activities of children and youth with SCI: higher caregiver education was associated with increased participation in more organised leisure activities.

Key factors across age groups

Our literature search did not reveal studies that investigated variables associated with participation solely in pre-school children. Only the study by Stevenson et al. (2006) included children of pre-school age, but unfortunately no separate analyses were reported for children in this age group.

Most studies included children and youth with a mean age of 10-11 years. For youth aged 13-18 years, no separate analyses were done. However, in several studies age did appear to be a variable that was associated with participation (King et al., 2009; Klaas et al., 2010; Law et al., 2004; Law et al., 2006; Maher et al., 2007; Majnemer et al., 2008; Morris et al., 2006; Voorman et al., 2006). Older children tended to participate in fewer activities and to do so less frequently than their younger peers (King et al., 2009; Klaas et al., 2010; Maher et al., 2007). This age effect was found for children with CP, SCI and groups of children with several diagnoses. One study focussed on the changes in participation levels over a three years period and made a distinction between predictors of change for younger and older children (King et al., 2009). Different variables were identified for younger children, 6-10 years of age. Governmental policies, behavioral functioning and household income were reported to be significant predictors of change in participation for children in this age range. For older children, 11-15 years of age, household income, caregiver's physical functioning and parent's ethnicity were significant predictors of change in participation. Lower income was associated with declines in participation. Better physical functioning and a non-Caucasian ethnicity were associated with a decline in frequency of participation for older children.

DISCUSSION

The purpose of this review was to systematically analyse the literature with the purpose of identifying variables associated with the frequency of participation in leisure activities for children and youth with various diagnoses of physical ability. This review focussed on identifying variables for different diagnostic and age groups.

Frequency of participation in leisure and social activities for children and youth with physical disabilities is associated with a variety of variables. The review showed gross motor function, manual ability, cognitive ability, communicative skills, age and gender to be the most important variables. Evidence suggests that these same variables are applicable to different diagnostic groups. Although differences in participation exist between different age groups, similar determinants of participation were identified for different age groups.

When analyzing studies of participation in different diagnose groups, it becomes apparent that most studies have focussed on children with CP and those studies are the most elaborate ones. These studies include a greater number of children and include a large set of measures to identify possible associations with frequency of participation. However, evidence found in the current analysis suggests that similar variables seem to apply to children with DCD, polyarticular arthritis, SCI when looking at their frequency of participation. However, studies including these diagnostic groups are few in number. Future research is therefore needed among more diverse populations of children with physical disabilities (e.g., children with spina bifida, congenital limb deformities, etc.) to obtain a more comprehensive view of the determinants of participation in specific diagnostic groups before a definitive answer can be given.

When age was examined as a determinant in participation, it was clear that most studies included children across a wide age range but did not perform separate analyses for different age groups. Only one study was able to identify different variables associated with level of participation for different age groups (King et al., 2009). The variables identified were associated only with some activity types measured with the Children's Assessment of Participation and Enjoyment (CAPE). The shortage of information on children of pre-school age could be due to the current lack of measures to assess participation in this group. Recently two measures have been developed suitable for assessing participation in children under the age of 6 years (Kemps, Siebes, Gorter, Ketelaar, & Jongmans, 2010; Rosenberg, Jarus, & Bart, 2010). It is expected that when participation measures for younger children become more widely used, knowledge on the participation of this group will grow. Knowledge of the determinants of participation in young children is needed to tailor early intervention services that anticipate the development of children with physical disabilities.

Some studies in this review presented a multidimensional model of the determinants of participation. Not only have they found different factors to be associated with frequency of participation, they also found a relatively low explained variance for the scores of the participation measure involved. This is an indication that participation in leisure activities is complex and not easily explained by simply a few factors. In rehabilitation care, participation is one of the main outcomes of treatment and it is considered one of the more important outcomes for parents and youth (Vargus-Adams & Martin, 2010). Improving participation in leisure activities should be undertaken by the whole rehabilitation team and treatment gains will probably only be reached through interventions aimed concurrently at the level of health condition, body functions, personal factors, and environmental factors.

Recently, there has been discussions about how to define and measure participation and attempts are being made to promote a clearer definition and more unified measurement of participation (Coster & Khetani, 2008; Dijkers, 2010; McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006; Whiteneck & Dijkers, 2009). In this review, different ways of measuring participation in leisure activities made it hard to compare studies because the domains and chapters of the ICF that were used were not explicitly stated. The authors encourage researchers to state clearly which activities they have incorporated in their research and how they have defined participation based on definitions and activities outlined in the ICF.

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Chapter 5

Predicting leisure participation of school aged children with cerebral palsy: Longitudinal evidence of child, family and environmental factors

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ABSTRACT

Objective: This longitudinal study aims to determine which child, family and environmental variables measured at 2 years of age predict leisure participation in formal and informal activities in school aged children with cerebral palsy (CP).

Methods: Parents of 46 children with CP (mean age at baseline: 2y 6mo, SD 0y 1mo; at follow-up: 6y 7mo, SD 0y 9mo; *N* = 26 boys, *N* = 20 girls; Gross Motor Classification System I = 30%, II = 7 %, III = 28%, IV = 24%, V = 11%) completed the Children's Assessment of Participation and Enjoyment (CAPE) indicating their child's participation. Multivariate regression models were used to identify early predictors of participation.

Results: Movement ability was a significant child related predictor for formal activities (R^2 17%, $p < 0.05$). Movement ability and social skills were most predictive (R^2 62%, $p < 0.00$) for informal activities. The feeling of being restricted in family participation was the single most predictive factor for formal and informal activities at family level (R^2 12%, $p < 0.05$, R^2 25%, $p < 0.05$). Type of daycare was the only environmental variable that was predictive, and only for informal activities (R^2 16%, $p < 0.05$). In the overall model movement ability was most predictive for leisure participation in formal activities (R^2 17%, $p < 0.05$). Movement ability and social skills are the most important predictors for informal leisure participation (R^2 62%, $p < 0.01$).

Conclusions: Several variables are found to be related to formal and informal participation at age 6. Movement ability and social skills at age 2 are most predictive of leisure participation when the child is 6 years old.

INTRODUCTION

Participation is defined as "someone's involvement in life situations" (World Health Organization, 2004). Leisure activities, often divided in formal and informal activities, are an important aspect of participation and are defined as voluntary recreation and leisure activities not required for school (King et al., 2003). King et al. (2003, p.65) have defined formal activities as 'structured activities that involve rules or goals and have a formally designated coach, leader or instructor'. Informal activities are defined as 'activities that have little or no prior planning and are often but not always, initiated by the child'. The ability to participate is a determinant of quality of life and should therefore be possible for all children, including those with disabilities who are known to be at risk for participation restrictions (Bult et al., 2010; Imms, Reilly, Carlin, & Dodd, 2008; Mc Manus, Corcoran, & Perry, 2008).

Children with cerebral palsy (CP) are at risk for experiencing limitations in their daily life including difficulties to participate in leisure activities (Maher, Williams, Olds, & Lane, 2007; Østensjø, Carlberg, & Vollestad, 2003; Tieman, Palisano, Gracely, & Rosenbaum, 2004). No longitudinal studies in children with CP, focussing on participation, have been undertaken. It is

not known which factors early in life are related to participation when the child is older. Since this information is important for rehabilitation professionals to determine which problems need to be addressed at an early age in a multidisciplinary setting, the aim of this longitudinal study is to determine which child, family and environmental variables measured at 2 years of age predict leisure participation when the child with CP is school-aged.

METHODS

This study was a follow-up of the PEdiatric Rehabilitation Research In the Netherlands (PERRIN) programme (Schuengel et al., 2009). The Medical Ethics Committee of the University Medical Center Utrecht and all participating centres in the Netherlands approved the PERRIN-study, as well as the follow-up described in this article.

Participants

Parents of 74 of the 100 children with CP who previously participated in the PERRIN CP 0-5 study were invited to participate again in the present study for a follow-up. The follow-up was done when the children were aged between 5-8 years of age.

Measures

For the purpose of variable selection three recently published reviews (Bult, Verschuren, Jongmans, Lindeman, & Ketelaar, 2011; Imms, 2008; Shikako-Thomas, Majnemer, Law, & Lach, 2008; Shikako-Thomas et al., 2009) were examined to identify variables related to participation in children with CP.

Dependent variable

Participation

The Children Assessment of Participation and Enjoyment (CAPE) was used. This is a self-report questionnaire that assesses participation in leisure activities of children and youth from 6 to 21 years (King et al., 2007), and has shown to be valid and reliable in the Dutch population (Bult et al., 2010).

Independent variables

Child variables

Information about gender was derived from the demographic variables. To assess the cognitive development of the child the Bayley Scales of Infant Development Second Edition (BSID-II) was used (Bayley, 1993). The presence of epilepsy at age 2 was obtained during the medical history taking with one of the parents. Gross motor capacity was determined with the Gross Motor Function Measure (GMFM-66) using the Gross Motor Ability Estimator (GMAE) software (Russell et al., 2000). The Vineland Adaptive Behavior Scale (VABS) (Duijn, Dijkxhoorn, Noens, Scholte, & Berckelaer-Onnes, 2009) was administered to gain insight in the child's communicative and social functioning and the daily living skills of the child. Performance of self-care-related activities and mobility-related activities assessed using the Pediatric Evaluation of Disability Inventory-NL (PEDI-NL) (Wassenberg-Severijnen & Custers, 2005). Quality of life of the child was assessed with the TNO AZL Pre-school Children Quality of Life Questionnaire (TAPQOL) (Bunge et al., 2005). For this study the scores of the 12 subscales of the TAPQOL were narrowed down to 4 scales covering physical, social, cognitive, and emotional functioning (Fekkes et al., 2000). To outline the behavioural characteristics of the child the Behaviour Rating Scale (BRS) of the BSID-II was used (Bayley, 1993).

Family variables

To measure parental stress the Nijmeegse Ouderlijke Stress Index-Kort (NOSI-K) (Brock, Vermulst, Gerris, & Abidin, 1992), a shortened version of the adapted Dutch version of the Parenting Stress Index (PSI), was administered. Parental coping was measured with the Utrechtse Coping Lijst (UCL) (Scheurs, Willige, Tellegen, & Brosschot, 1988). The social, practical and financial support that parents experience was determined using a 3-point Likert scale (much, little or no support). Family participation and parent's personal participation in activities was assessed using semi-structured interviews with one or both parents during the assessment with the child (Rentinck, Gorter, Ketelaar, Lindeman, & Jongmans, 2009). A standardized question from Statistics Netherlands (Centraal Bureau voor de Statistiek, CBS) was used to get insight in the quality of life of the parents of children with CP.

Environmental variables

During the anamnesis parents were asked what kind of day-care their child attended. Type of day-care was subdivided in special day-care (e.g., therapeutic toddler groups), regular day-care (e.g., day-nursery) or children not receiving any day-care. For the measure of social economic

situation the parents provided their postal code completing the demographic questions. The postal code was used to derive a coding from Statistics Netherlands (CBS) (Knol, 1998). This coding was reduced to three categories representing the social economic situation of the family; 'average', 'below average' and 'above average'.

Statistical analysis

Following univariable stepwise forward regression analyses, significant predictors ($p < 0.00$) were used to compose three optimal multivariable regression models (child, family and environmental variables). In order to find the most predictive variables across the six models two optimal regression models (formal and informal participation) were constructed using the variables that were significant predictors from the optimal multivariable child, family and environmental models.

RESULTS

A total of 46 parents, of children with CP who previously participated in the PERRIN CP 0-5 study, gave their written consent for participating in the present study and completed the CAPE. The age of the children at baseline was 2y 6mo, SD 0y 1mo. The group of children that was not included in this study because the parents did not return the completed CAPE questionnaire was comparable to the group that did participate considering age, gender and Gross Motor Function Classification System (GMFCS) level. The CAPE was completed for 26 boys and 20 girls, aged between 5-8 years old (mean age 6y 7mo, SD 0y 9mo). Characteristics of the children are shown in Table 5.1. Mean CAPE intensity scores for formal activities was 0.70 ± 0.52 and for informal activities was 2.23 ± 0.65.

During preparatory analyses, three variables were excluded because of colinearity. GMFCS level was used for descriptive purposes only because of high correlation with the GMFM scores (Pearson's $r = 0.91$, $p < 0.01$). PEDI scores for mobility and self-care were also excluded because of high correlation with the GMFM scores (respectively Pearson's $r = 0.93$, $p < 0.001$, $r = 0.83$, $p < 0.001$). Tables 5.2 to 5.4 show the univariate regression analyses and significant relations for subsequently child, family and environmental variables.

Table 5.1 Child characteristics of the study sample

Child characteristics	N	%
Age (years)		
5	7	15.2
6	17	37.0
7	17	37.0
8	5	10.8
Gender		
Boys	26	56.5
Girls	20	43.5
GMFCS level		
I	14	30.4
II	3	6.5
III	13	28.3
IV	11	23.9
V	5	10.9

Multivariable analysis

Child, family and environmental models

Multivariable analysis of the child variables show that for formal activities only gross motor function was predictive of later participation explaining 17% of variance ($R^2 = 0.17$, $p < 0.05$). For the informal activities movement ability and social functioning of the child were most predictive together explaining 62% of variance ($R^2 = 0.62$, $p < 0.001$).

Multivariable analysis of the parent variables show that for both the formal and informal activities family participation measured at age 2.5 years is predictive, explaining 12% of variance for formal activities ($R^2 = 0.12$, $p < 0.05$) and 25% for informal activities ($R^2 = 0.25$, $p < 0.05$).

Multivariable analysis of the environmental variables show that for the formal activities no significant predictors can be identified. For the informal activities type of day-care at age 2.5 years is predictive of participation when the child is school aged explaining 16% of variance ($R^2 = 0.16$, $p < 0.05$).

Overall predictors

To identify which predictors show the strongest association with participation within the constructed formal and informal activity models, the significant predictors from the three separate models were used to perform a final analysis on formal and informal activities. In the

Table 5.2 Univariable associations between child variables measured at 2.5 years of age and formal and informal participation at 5-8 years of age

		Formal			Informal		
		B	95% CI	R^2	B	95% CI	R^2
Gender	Demographic information	0.03	-0.30 – 0.35	0.01	0.21	-0.17 – 0.59	0.03
Mental function	BSID-II MS	0.01	0.00 – 0.02	0.09	0.02	0.01 – 0.03	0.49**
Epilepsy	Anamnesis	-0.20	-0.57 – -0.17	0.03	-0.54	-0.95 – -0.12	0.14*
Movement ability	GMFM	0.02	0.01 – 0.03	0.17*	0.02	0.01 – 0.04	0.32**
Communication	VABS - Communication domain	0.03	0.00 – 0.05	0.11*	0.05	0.03 – 0.07	0.34**
Daily living skills	VABS - Daily living skills	0.04	0.00 – 0.08	0.10*	0.09	0.05 – 0.12	0.32**
Social functioning	VABS - Socialization domain	0.05	0.01 – 0.08	0.15*	0.10	0.07 – 0.13	0.58**
Quality of life	TAPQOL - Physical functioning	0.01	0.00 – 0.00	0.01	0.01	0.00 – 0.01	0.01
	TAPQOL - Emotional functioning	0.02	0.00 – 0.01	0.07	0.02	0.00 – 0.04	0.08
	TAPQOL - Cognitive functioning	0.01	0.00 – 0.02	0.09	0.01	0.00 – 0.02	0.13*
	TAPQOL - Social functioning	0.00	-0.01 – 0.01	0.00	0.01	-0.01 – 0.01	0.00
Behavioural characteristics	BSID-II - Behaviour scale	0.01	-0.03 – 0.04	0.01	0.05	0.02 – 0.09	0.22*

BSID-II, Bayley Scales of Infant Development-Second edition; GMFM, Gross Motor Function Measure; VABS, Vineland Adaptive Behavior Scales; TAPQOL, TNO AZL Pre-school Children Quality of Life Questionnaire.
* $p < 0.05$, ** $p < 0.001$

Table 5.3 Univariable associations between family variables measured at 2.5 years of age and formal and informal participation at 5-8 years of age

		Formal			Informal		
		B	95% CI	R^2	B	95% CI	R^2
Parental stress	NOSI-K – mother	-0.01	-0.02 – 0.01	0.03	-0.01	-0.24 – 0.00	0.12*
	NOSI-K – father	0.00	-0.01 – 0.01	0.00	-0.02	-0.26 – -0.01	0.18*
Coping	UCL – active coping mother	0.02	-0.15 – 0.18	0.00	-0.01	-0.18 – 0.17	0.00
	UCL – passive coping mother	-0.05	-0.22 – 0.12	0.01	-0.09	-0.27 – 0.01	0.02
	UCL – active coping father	0.04	-0.17 – 0.24	0.00	0.06	-0.18 – 0.30	0.01
	UCL – passive coping father	0.06	-0.12 – 0.25	-0.01	-0.06	-0.27 – 0.16	0.01
Social support – practical support	Mother	-0.02	-0.35 – 0.32	0.00	-0.03	-0.42 – 0.36	0.00
	Father	-0.02	-0.37 – 0.33	0.00	0.22	-0.19 – 0.62	0.03
Social support – emotional support	Mother	0.09	-0.27 – 0.44	0.01	-0.12	-0.54 – 0.30	0.01
	Father	-0.09	-0.44 – 0.26	0.01	-0.08	-0.49 – 0.33	0.00
Social support – financial support	Mother	-0.02	-0.54 – 0.49	0.00	-0.06	-0.68 – 0.57	0.00
	Father	-0.15	-0.83 – 0.53	0.01	0.16	-0.58 – 0.91	0.01
Family participation	'Typical' participation (reference)			0.12*			0.25*
	Restricted participation vs reference	-0.33	-0.66 – -0.01		-0.48	-0.84 – -0.12	
	Completely restricted participation vs reference	-0.44	-1.00 – 0.12		-0.10	-1.64 – -0.38	
Personal participation	'Typical' participation			0.06			0.05
	Restricted participation	-0.28	-0.64 – 0.07		-0.27	-0.70 – -0.17	
	Completely restricted participation	-0.16	-0.61 – 0.30		0.06	-0.50 – 0.62	
Quality of life parents	CBS – quality of life mother	0.11	0.00 – 0.23	0.09	0.15	0.02 – 0.29	0.11*
	CBS – quality of life father	0.07	-0.05 – 0.22	0.04	0.17	0.03 – 0.30	0.14*

NOSI-K, Nijmeegse Ouderlijke Stress Index–Kort; UCL, Utrechtse Coping Lijst; CBS, Centraal Bureau voor de Statistiek (Statistics Netherlands).
* $p < 0.05$, ** $p < 0.001$

Table 5.4 Univariable associations between environmental variables measured at 2.5 years of age and formal and informal participation at 5-8 years of age

		Formal			Informal		
		B	95% CI	R^2	B	95% CI	R^2
Type of day-care	Regular (reference)			0.09			0.16*
	No daycare vs reference	-0.34	-0.85 – 0.17		-0.66	-1.22 – -0.11	
	Specialised daycare vs reference	-0.31	-0.65 – 0.04		-0.41	-0.81 – -0.01	
Socio-economic situation	Average (reference)			0.18			0.02
	Low – below average vs reference	-0.02	-0.50 – 0.20		-0.05	-0.25 – -0.57	
	Above average – high vs reference	-0.15	-0.56 – 0.52		0.16	-0.69 – - 0.59	

* $p < 0.05$, ** $p < 0.001$

final multivariable model for the formal activities movement ability was the single strongest predictor of participation in leisure activities. This variable explained 17% of variance ($R^2 = 0.17$, $p < 0.05$). For the informal activities movement ability and social skills were the best overall predictors of participation. Together they explained 62% of variance ($R^2 = 0.62$, $p < 0.001$).

DISCUSSION

This longitudinal study is the first to show that predictors of participation in school-aged children with CP can be identified at an early age. The results show that movement ability and social skills at the age of two are the main predictors of participation in leisure activities when the child is school aged. For the informal activities a very high explained variance of 62% was found, which has not been found in previous studies (Imms, Reilly, Carlin, & Dodd, 2009).

At the family level the feeling of being restricted as a family is most predictive for participation restrictions. This is an important finding because parents are considered to be of crucial importance to their children's participation in providing opportunities to participate in activities (Rentinck et al., 2009). In several studies the family activity orientation is considered to be of great importance to the activities the child engages in (Palisano et al., 2011). The less active orientation of the family when the child is school aged could be a result of the restrictions

parents felt when the child was young. Therefore this study underlines the importance of early intervention for children with physical disabilities and their parents to prevent future challenges in relation to participation.

For informal activities a large explained variance was found. However participation in formal activities is harder to predict. Imms et al. (2009) have shown that preference is one of the stronger predictors of engagement in formal activities. In turn the preference for an activity could be influenced by the family's preference or the availability of services around the child. In order for health care professionals to support children in participating in organised activities it is important to know which factors are most important so they can be addressed in the early intervention services they provide.

Although this is the first longitudinal study reporting predictors of participation, a limitation of our study is still the relatively small sample size. There were only 46 parents participating in this study. Future studies should include more parents and consider including a range of environmental variables specific for that country in order to get more insight in environmental variables.

Conclusion

This study has shown that movement ability and social skills at 2.5 years are the most important predictors for later participation in leisure activities in school-age children with CP. At the child level movement ability and social skills showed to be the most important factors. At the family level the feeling of being restricted as a family is most predictive for participation restrictions. At an environmental level type of day-care is predictive for later participation.

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Chapter 6

Participation in leisure activities of children and adolescents with and without cerebral palsy: comparing Spain and The Netherlands

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ABSTRACT

Purpose: To assess participation in leisure activities of children and adolescents with Cerebral Palsy (CP) in Spain and The Netherlands, comparing findings with typically developing children and adolescents in both countries, and to identify variables related to participation in leisure activities for children and adolescents with CP.

Method: The participants were 149 children and adolescents with CP (114 in Spain [43 girls and 71 boys, mean age 12.2 years, range 8-18 years] and 35 in The Netherlands [17 girls and 18 boys, mean age 13.1 years, range 8-18 years]), and 332 typically developing children and adolescents (199 in Spain [102 girls and 97 boys, mean age 13.2 years, range 8-18 years] and 133 in The Netherlands [71 girls and 62 boys, mean age 12.2 years, range 8-18 years]) who completed the Children's Assessment of Participation and Enjoyment (CAPE) in its Spanish or Dutch version, respectively.

Results: Spanish and Dutch children with CP had similar scores in overall diversity and intensity of participation, but there were significant differences in the formal domain and skill-based leisure activities, where the Spanish group scored significantly higher than the Dutch group. Similar results were found in the reference groups. The regression model for the children with CP that included the child variables, type of school and country explained 14% of the variance in overall diversity and intensity, and 28% in diversity in recreational and 22% in active physical activities.

Conclusion: The differences between the two countries regarding participation in leisure activities of children with CP may be due to culture and environment.

INTRODUCTION

Over the last few years there has been a growing interest in participation of children and adolescents. Participation is defined by the International Classification of Functioning, Disability and Health (ICF-CY) as involvement in life situations (WHO, 2004).

Participation is important for all children to develop their identity and become active, independent members of society (Michelsen et al., 2009). Leisure is defined as those activities the individual freely chooses to participate in during their spare time because they find such activities enjoyable (Majnemer et al., 2008). Through participation in leisure activities children develop communication skills, build friendships and gain autonomy and self-efficacy (Law et al., 2004). Thus, leisure activities are essential for the development of all children, particularly for children with disabilities.

Studies have shown that children and adolescents with Cerebral Palsy (CP) and other physical disabilities experience restrictions in participation, spend more time in quiet and sedentary activities and may suffer bullying and social exclusion (Donkervoort et al., 2007; Engel-Yeger et al., 2009; Imms, Reilly, Carlin, & Dodd, 2008; Lindsay & McPherson, 2012; Majnemer et al.,

2008; Michelsen et al., 2009). It has been suggested that there is a negative effect of the physical, social, or attitudinal environment contributing to the participation restrictions (Forsyth, Colver, Alvanides, Woolley & Lowe, 2007; Jönsson, Ekholm, & Schult, 2008; Majnemer et al., 2008¸ Rosenbaum, 2007).

The International Classification of Function disability and health (ICF-CY) model states that personal and environmental factors influence participation either as a barrier or a facilitator (WHO, 2004). Given that the environment is a potentially modifiable factor, it is important to identify which features of the physical, social and attitudinal environments are barriers to participation. For example, Hammal, Jarvis, & Colver (2004) showed that level of participation of children with similar types and severity of CP varied according to their place of residence.

As participation is thought to be influenced by environmental factors such as where children live, findings may differ from one country to another. However, evidence about the differences between countries is scarce. One of the major studies presently available is the SPARCLE study (Fauconnier et al., 2009) in which participation in different European countries was assessed. However, Fauconnier et al. (2009) did not specifically focus on participation in leisure activities in children with CP and no comparison with healthy peers was made. Without this comparison it remains unclear whether the differences found between the countries are due to cultural influences or are specific for children with CP.

The present study aimed to identify if there are differences between the levels of leisure participation of children and adolescents with CP and typically developing children and adolescents who live in Spain and The Netherlands, and obtain explicative models in both countries. Specifically, we intended:

1. To evaluate the diversity and intensity of leisure participation of children and adolescents with CP in Spain and the Netherlands, comparing findings with leisure participation of typically developing children in both countries (reference group);
2. To describe the type of leisure activities that the children and adolescents with CP and their typically developing peers participated in, in both countries;
3. To examine variables related to participation in leisure activities for children and adolescents with CP in both countries.

METHOD

This paper reports a cross-country study on participation in leisure activities in children and adolescents with and without CP in two countries, Spain and The Netherlands. The study made use of data collected in two earlier studies on the translation and validation of the *Children's Assessment of Participation and Enjoyment* (CAPE) in both countries (Badia et al., 2011; Bult et al., 2010).

Participants

Children and adolescents with CP, all levels of the Gross Motor Function Classification System (GMFCS) (Palisano et al., 1997); and aged between 8 and 18 years old were selected in both countries. Children and adolescents with low IQ scores (below 50) who could not answer the questions in the CAPE (independently or with assistance) were excluded. For this study, we defined children to be between 8-12 years old and adolescents between 13-18 years old.

The Spanish CP sample came from the 16 Associations Caring for People with Cerebral Palsy and Related Disabilities (ASPACE) in 7 different regions of Spain and from 3 regular schools. The Dutch CP sample consisted of children and adolescents from 7 schools (2 special and 5 regular) in 3 regions of The Netherlands.

In both countries children and adolescents with CP and their parents were contacted by a letter with information on the study. After both the children and the parents who wanted to participate had signed and returned the written consent form, the interviews were arranged.

A reference group of typically developing children (aged between 8 and 18 years old) was recruited in both countries, from regular schools in the same regions as the schools for special education and the ASPACE centers.

Procedure and measures

Ethical approval was provided in the two countries (Ethic Committee of the Universidad de Salamanca Spain and the University Medical Center Utrecht – The Netherlands).

Participation was measured using the CAPE. The CAPE is a measure for participation in leisure activities which is appropriate for children and young people aged 6 to 21 years, with or without disabilities (King et al., 2007). The children and adolescents report for each of the 55 items if the activity was performed in the previous 4 months (diversity), and if so, how often (intensity), with whom, where and how much they enjoyed that activity. For the purpose of the present study the diversity and intensity CAPE scores were used.

Participation can be evaluated using the overall scores, i.e., calculated for all 55 activities or can be evaluated using domain scores in formal activities (15 items) and informal activities (40 items). It is also possible to obtain scores for activities types: Recreational (12 items), Social (10 items), Active Physical (13 items), Skill-Based (10 items) and Self-Improvement (10 items).

Evidence of internal consistency, test–retest reliability, content validity, construct validity, convergent and discriminant validity of the CAPE's original version have been reported (King et al., 2007). In this study two translated and validated versions of CAPE were used: the Dutch version (Bult et al., 2010) and the Spanish version (Badia et al., 2011).

For the samples of children with CP, the CAPE was completed by the child or adolescent in a one-on-one session which was administrated by trained research assistants in the ASPACE center (in Spain) or in the school (in The Netherlands). Parents provided information about the socio-demographics characteristics (as age and gender). Also, information about the GMFCS, the intellectual level (IQ) and the type of school (regular or special) was obtained from the medical records in the center or school which each child attended.

For the reference group, in each country the CAPE was completed by each child or adolescent in the school. For the Dutch children aged 8 to 12 years the CAPE was administered in a one-on-one session with a trained research assistant. Youth aged 12 years and older filled out the CAPE in the classroom after instruction by a trained research assistant. The research assistant was also present during the assessment to answer questions. For the Spanish children the CAPE was administered in a group session in the classroom after instruction by a research assistant and the teachers facilitated the distribution and collection of questionnaires. Each participant provided information about gender and age.

Statistical analysis

Descriptive statistics (frequency, means and standard deviations) were used to summarize the sample characteristics and to describe diversity and intensity of participation.

Between-country differences on diversity and intensity of participation were assessed using Student *t*-tests for independent samples. These analyses were utilized for the group of children with CP and for the reference group for all domains and activity types of the CAPE.

To gain more insight in the possible differences in diversity of participation between children in Spain and in the Netherlands, the percentages of the children that participated in each of the 55 activities of the CAPE were calculated, both in the CP and the reference groups.

In order to obtain parsimonious explicative models of the participation in leisure activities in children and adolescents with CP who live in both countries, multiple linear regression analysis – forward selection – was used.

Statistical analyses were carried out with SPSS, version 17. The level of statistical significance was set at 0.05.

RESULTS

Group characteristics

The characteristics of the participants with CP and the reference group are summarized in Table 6.1. Data were available for a total of 149 children and adolescents with CP (114 in Spain and 35 in The Netherlands) and 332 typically developing children and adolescents (199 in Spain

Table 6.1 Group characteristics of the children with CP and the Reference group in Spain and in The Netherlands

Variables	Spain CP (*N* = 114)	Spain Reference (*N* = 199)	The Netherlands CP (*N* = 35)	The Netherlands Reference (*N* = 133)
Age (mean; SD; range)	12.2; 3.0; 8-18	13.2; 3.1; 8-18	13.1; 2.8; 8-18	12.2; 2.6; 8-18
Gender				
Female	43 (37.7%)	102 (51.3%)	17 (48.6%)	71 (53.4%)
Male	71 (62.3%)	97 (48.7%)	18 (51.4%)	62 (46.6%)
Intellectual disability				
None-mild (IQ >70)	80 (70.2%)	-	27 (77.1%)	-
Moderate (IQ 50-70)	34 (29.8%)	-	6 (17.1%)	-
Missing	0 (0%)	-	2 (5.7%)	-
Kind of school				
Regular	111 (97.4%)	199 (100%)	5 (14.3%)	133 (100%)
Special	1 (0.9%)	0 (0%)	30 (85.7)	0 (0%)
Missing	2 (1.8%)	0 (0%)	0 (0%)	0 (0%)
GMFCS				
Level I	39 (34.2%)	-	18 (51.4%)	-
Level II	22 (19.3%)	-	7 (20.0%)	-
Level III	24 (21.1%)	-	7 (20.0%)	-
Level IV	19 (16.7%)	-	2 (5.7%)	-
Level V	10 (8.8%)	-	1 (2.9%)	-

and 133 in The Netherlands). All variables considered were tested for significant differences (independent samples *t*-test). In the CP group we did not find any significant differences between both countries, except for type of school (97.4% of the Spanish children and adolescents attended regular school compared to 14.3% of the Dutch children and adolescents), and GMFCS levels (25.5% of the Spanish children and adolescents within GMFCS levels IV and V compared to 8.6% of the Dutch children and adolescents). In the reference group, both countries were similar concerning age and gender.

Participation diversity

Children with CP in Spain and in The Netherlands had comparable scores of overall diversity of participation, as outlined in Table 6.2. The Spanish children with CP reported higher scores in the formal domain and in the skill-based activities. No significance differences were found between the two countries in the scores of the other domains and activity types. The mean score of 4.3 obtained in the formal domain by the Spanish group and the mean score of 2.7 for the Dutch group represents, respectively 28.6% and 18% of the total formal activities included in the CAPE (15/55). On the other hand, the Spanish group reported a mean score of 20.6 and the Dutch group a mean score of 21.7, representing respectively 51.5% and 54.2% of total informal activities (40/55).

Table 6.2 CAPE diversity scores for children and adolescents with and without CP in Spain and in The Netherlands

CAPE domains (max. scores)	Spain CP (*N* = 114)	The Netherlands CP (*N* = 35)	Spain Reference (*N* = 199)	The Netherlands Reference (*N* = 133)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Diversity overall (55)	24.8 (6.5)	24.7 (7.6)	26.1 (7.7)	29.0 (5.4)*
Diversity formal (15)	4.3 (2.3)**	2.7 (2.5)	4.5 (2.2)***	3.6 (1.9)
Diversity informal (40)	20.6 (5.0)	21.7 (6.0)	21.2 (6.3)	24.3 (4.8)***
Diversity recreational (12)	7.6 (2.1)	7.8 (2.5)	7.0 (2.5)	7.9 (2.2)**
Diversity social (10)	7.0 (1.7)	7.1 (1.8)	6.9 (1.8)	7.4 (2.0)*
Diversity active physical (13)	3.2 (1.9)	3.4 (2.0)	4.4 (2.3)	4.6 (1.9)
Diversity skill-based (10)	3.2 (1.8)**	1.9 (1.9)	2.9 (1.6)	2.8 (1.6)
Diversity self-improvement (10)	4.6 (1.8)	4.3 (2.1)	5.2 (1.9)	5.2 (1.9)

SD, standard deviation.
*** $p < 0.001$, ** $p < 0.01$, * $p < 0.05$

In the reference group, the children from The Netherlands reported higher scores on overall diversity, the informal domain and in social and recreational activities. As in the CP group, the Spanish reference group reported higher scores in the formal domain compared to the Dutch sample.

Participation intensity

In the CP group the intensity mean scores ranged from 0.7 (formal) to 3.2 (recreational) in The Netherlands and from 1.1 (active physical) to 3.1 (social) in Spain (Table 6.3). These results were not very different from those obtained with the reference groups, where mean scores ranged from 1.0 (formal) to 3.3 (recreational) in The Netherlands and from 1.5 (formal) to 3.2 (social) in Spain (Table 6.3).

Children with CP in The Netherlands participated less frequently than children with CP in Spain in the formal, social, skill-based and self-improvement activities of the CAPE.

For the reference groups, the results were similar to the CP group in the formal and skill-based activities, where the Dutch children participated less frequently than Spanish children. However, Dutch children in the reference group participated more frequently in informal and in recreational activities compared to their Spanish peers.

Table 6.3 CAPE intensity scores for children and adolescents with and without CP in Spain and in The Netherlands

CAPE domains (Scores 1-7)	Spain CP ($N = 114$)	The Netherlands CP ($N = 35$)	Spain Reference ($N = 199$)	The Netherlands Reference ($N = 133$)
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Intensity overall	2.1 (0.5)	2.0 (0.6)	2.3 (0.7)	2.3 (0.5)
Intensity formal	1.4 (0.7)***	0.7 (0.5)	1.5 (0.7)***	1.0 (0.5)
Intensity informal	2.4 (0.6)	2.5 (0.7)	2.5 (0.7)	2.8 (0.6)**
Intensity recreational	3.0 (0.9)	3.2 (1.2)	2.8 (1.2)	3.3 (1.1)***
Intensity social	3.1 (0.8)*	2.7 (0.9)	3.2 (0.9)	3.0 (0.9)
Intensity active physical	1.1 (0.7)	1.1 (0.7)	1.6 (0.8)	1.7 (0.7)
Intensity skill-based	1.6 (0.9)***	0.8 (0.8)	1.5 (0.8)**	1.2 (0.8)
Intensity self-improvement	2.4 (0.8)**	1.9 (1.1)	2.7 (1.0)	2.5 (0.9)

SD, standard deviation.
*** $p < 0.001$, ** $p < 0.01$, * $p < 0.05$

Percentage of CAPE's activities

Table 6.4 shows differences between Spain and The Netherlands in 20 activities done most often in both groups of children with CP and the reference groups. Overall, there were many differences between the countries for the type of activities the children with CP participated in. These findings were comparable for the reference groups.

Table 6.4 Percentage of children (CP and Reference) participating in an activity: comparing countries

Item CAPE	Spain CP (Reference)		The Netherlands CP (Reference)	
	%	Rank	%	Rank
Hanging out* (Informal-Social)	97 (98)	1 (1)	49 (58)	24 (24)
Watching TV (Informal-Recreational)	94 (90)	2 (4)	97 (99)	1 (1)
Entertaining others* (Informal- Social)	90 (80)	3 (10)	74 (93)	13 (3)
Visiting (Informal-Social)	90 (91)	4 (3)	94 (92)	2 (5)
Going to a party (Informal-Social)	85 (78)	5 (12)	86 (90)	4 (6)
Doing homework* (Informal-Self-improvement)	85 (85)	6 (7)	63 (82)	15 (9)
Playing board or card games (Informal-Recreational)	83 (88)	7 (5)	74 (92)	11 (4)
Going for a walk or a hike* (Informal-Recreational)	81 (64)	8 (19)	54 (71)	20 (18)
Listening to music (Informal-Social)	80 (83)	9 (8)	86 (87)	5 (8)
Playing computer or video games* (Informal-Recreational)	80 (88)	10 (6)	91 (95)	2 (2)
Talking on the phone (Informal-Social)	77 (92)	11 (2)	74 (77)	12 (13)
Doing crafts, drawing or coloring (Informal-Recreational)	75 (76)	12 (14)	71 (76)	14 (14)
Playing with things or toys* (Informal-Recreational)	74 (49)	13 (23)	57 (57)	17 (25)
Doing gymnastics* (Formal-Skill-based)	71 (80)	14 (40)	3 (25)	55 (41)
Shopping* (Informal-Self-improvement)	68 (65)	15 (18)	83 (79)	6 (10)
Reading (Informal-Self-improvement)	66 (67)	16 (16)	57 (78)	18 (11)
Going on a full day outing* (Informal-Social)	61 (30)	17 (38)	80 (74)	9 (16)
Going to the movies* (Informal-Social)	60 (56)	18 (21)	80 (75)	8 (15)
Swimming (Formal-Skill-based)	56 (31)	19 (34)	49 (49)	25 (30)
Writing letters (Informal-Self-improvement)	55 (83)	20 (9)	54 (67)	19 (19)

Top 20 activities sorted in descending order for children with CP in Spain, comparing with children with CP in The Netherlands and with children in the reference groups in both countries.
*Activities in which the difference in percentage of children performing the activity in the previous 4 months was at least 10%.

For 10 of the 20 activities there were differences between Spain and The Netherlands of more than 10% of children participating in that specific activity. Hanging out, for example, is the activity performed by most of the Spanish children in the CP group (97%), while this activity was 24th in the rank order of activities (49%) for the Dutch children with CP. Interestingly, the same differences were observed in the reference groups.

The largest difference between the countries for the children with CP was observed in Doing gymnastics, which was performed by 71% of the children with CP in Spain (14th in rank order), while only 3% (55th in rank order) of the Dutch children with CP performed this activity. On the other hand, there were similarities between the countries in percentage of children with CP participating in activities, such as Watching TV (97%, 1st in rank order in The Netherlands and 94%, 2nd in rank order in Spain), Going to a party (86%, 4th in rank order in The Netherlands and 85%, 5th in rank order in Spain), and Talking on the phone (77%, 11th in rank order in Spain and 74%, 12th in rank order in The Netherlands).

Determinants of participation

The results of the multiple regression analyses in the CP group ($N = 149$) are presented in Table 6.5 (Diversity) and Table 6.6 (Intensity).

Table 6.5 Multiple linear regression for diversity of participation in children with CP ($N = 149$)

	Diversity	Formal	Informal	Recreational	Social	Active Physical	Skill-based	Self-improvement
Variables	β	β	β	β	β	β	β	β
Country	.030	-.352*	.059	.018	.174	-.142	-.245	.223
Age	-.199*	-.075	-.198*	-.490***	-.029	-.026	-.151	.073
IQ level	.004	.051	-.022	-.047	.129	.018	.069	-.086
Gender	.160*	.129	.156	.149*	.208*	-.028	.134	.092
School	-.066	.080	-.013	.066	-.163	.158	-.044	-.376*
GMFCS	-.275**	-.095	-.235**	-.136	.062	-.470***	-.119	-.183*
R^2	.14	.10	.13	.28	.06	.22	.13	.09

Spain $N = 114$; The Netherlands $N = 35$.
*** $p < 0.001$, ** $p < 0.01$, * $p < 0.05$
Variables: Country: 1 Spain, 2 Netherlands; Age: 1 children, 2 adolescents; IQ level: 1above 70, 2 50-70; Gender: 1 Boys, 2 Girls; School: 1 Regular, 2 Special. The GMFCS was used as a scale.

Table 6.6 Multiple linear regression for intensity of participation in children with CP (*N* = 149)

	Intensity	Formal	Informal	Recreational	Social	Active Physical	Skill-based	Self-improvement
Variables	β	β	β	β	β	β	β	β
Country	-.066	-.437*	-.038	.120	-.059	-.186	-.229	.007
Age	-.140	-.073	-.147	-.414***	.095	.026	-.159	.091
IQ level	-.012	.004	-.021	.035	.091	-.024	.039	-.108
Gender	.144	.128	.109	.159*	.145	-.035	.131	.080
School	-.114	.045	.028	-.011	-.136	.121	-.116	-.323
GMFCS	-.296***	-.149	-.225**	-.107	.001	-.475***	-.106	-.223**
R^2	.14	.17	.08	.21	.06	.21	.16	.13

Spain *N* = 114; The Netherlands *N* = 35.
*** $p < 0.001$, ** $p < 0.01$, * $p < 0.05$
Variables: Country: 1 Spain, 2 Netherlands; Age: 1 children, 2 adolescents; IQ level: 1above 70, 2 50-70; Gender: 1 Boys, 2 Girls; School: 1 Regular, 2 Special. The GMFCS was used as a scale.

Regarding diversity, the full model that included the child-related' variables age, gender, GMFCS, IQ level and type of school, and country, explained 14% of the variance in overall diversity, 28% in recreational and 22% in the active physical activity type. GMFCS level, gender and age contributed significantly to this model. Children with a better motor function participated more in overall diversity (β = –.275), the informal domain (β = –.235), self-improvement (β = –.183) and active physical activities (β = –.470). Girls participated more than boys in overall diversity (β = .160), recreational (β = .149) and social activities (β = .208). Children aged 8-12 years of age participated in more diverse activities than adolescents, 13-18 years of age (overall diversity β = –.199), in the informal domain (β = –.198) and in recreational activities (β = –.490). The country variable was significant only for the formal domain, where Spanish children with CP participated in more activities compared with the Dutch children with CP (β = –.352).

For the intensity of participation, the results were comparable to the diversity of participation. The model with the same variables explained 17% of the variance in formal, 21% in recreational and 21% in active physical.

In the same way, GMFCS level was the variable significantly related to most activity types, i.e., children with higher motor function had higher scores in overall intensity (β = –.296), in the informal domain (β = –.225), and in self-improvement (β = –.223) and active physical activities

(β = −.475). Gender and age were significantly related to recreational activities, where girls participated more frequently than boys (β = .159), and children participated more frequently than adolescents (β = −.414). Again the variable country was significantly related only to the formal activities domain, where the Spanish children with CP participated more often in these activities than the Dutch children with CP (β = −.437).

DISCUSSION

This study compared the participation of children and adolescents with CP in Spain and in The Netherlands. Spanish and Dutch children and adolescents with CP had similar scores in diversity of participation, but there were significant differences in the formal domain and skill-based activities, where Spain had more diverse scores.

The results regarding intensity of participation show that Spanish children and adolescents with CP, do formal activities and skill-based more often, indicating the same pattern of results found in diversity of participation. Alike results were shown with the reference group which confirms that the pattern is more culturally determined than related to disability.

It is important to emphasize that in both countries, children and adolescents with CP participated less often in formal activities compared to informal activities. The reduced participation in formal activities observed in children and adolescents with CP in this study and in other studies with different samples (Imms et al., 2008; Klaas, Kelly, Gorzkowski, Homko, & Vogel, 2010; Majnemer et al., 2008) is of concern because when young people with disabilities do participate in formal activities, they are more socially engaged, reinforcing the importance of this type of activity as a potential bridge to expanding social networks and experiences (Klaas et al., 2010). Additionally, Law et al. (2006) have showed that the informal activities may be more adversely affected by physical or institutional environmental barriers. The differences in engagement in formal activities found in the samples in the current study may reflect Spanish and Dutch cultural aspects of the two countries. In the same way, the culture and context may partially explain the differences found in skill-based activities. For example, one study with a large sample of children with CP – the SPARCLE study (Fauconnier et al., 2009) - found substantial variations in participation between children in countries in Europe, where children in Denmark showed higher participation levels compared to the others countries evaluated. According to the authors, these results might be explained by the regional policies, legislation and physical environment in the different countries. For example, in Denmark after school clubs are provided by the state which are attended every day by most of children up to age 12, with or without disability. In France and Ireland special transport for disabled children is only

provided for going to school, in the UK it depends on the local authority, in Italy it is provided but subject to budgetary limitations, while in Denmark, Sweden and Germany transportation to school is extensively covered. Only Sweden and Denmark have central national resources which facilitate information to families with a child with disability about assistive technology. Moreover, Sweden and Denmark have a strong tradition of state provided services and care for children, while France, Germany, Ireland and Italy have a profile which focuses more on family care (Colver et al., 2011; Fauconnier et al., 2009; Michelsen et al., 2009). These findings suggest that some countries promote participation more than others through policies and regulation at national level (Fauconnier et al., 2009).

The fact that in the present study we were able to include data on participation in leisure activities of typically developing children in both Spain and The Netherlands, helps to expand the understanding of patterns of participation in children and adolescents with CP. For example, when analyzing the results of diversity in the formal activities domain in the reference groups, we observed the same differences between countries as in the group of children with CP, where the Spanish sample conducted more formal activities than the Dutch sample. A recent survey on 'Children and the Future' held in Spain indicates that it is common for parents to enrol their children in various types of formal activities and that children begin to participate in such activities at an early age (Mary-Klose, Mary-Klose, Vaquera, & Argeseanu, 2010). In The Netherlands engagement in organized activities is initiated by the parent and the child themselves. Although a lot of groups and clubs are available and it is common to enrol your child in one or two groups or classes, the results of the present study show that this happens less frequently for Dutch children compared to Spanish children. Although Dutch children participate in fewer activities and do so less frequently, they participate more and more frequently in informal activities. Apparently children in The Netherlands participate more in spontaneous activities in or around the house instead of organised activities.

Moreover, Spanish children and adolescents with CP take part more often in social and self-improvement activities than Dutch children and adolescents with CP, which was not observed in the reference groups. When considering the types of activities included in these two domains, one can argue that the type of school may be related to this. As in the Spanish sample 97.4% attends a regular school, while the majority of the children with CP in the Dutch sample (85.7%) attend a school for special education. Given that Dutch children with CP spend more time at school compared to typically development children (since special schools have a longer school day compared to regular schools), this results in less time for extracurricular activities such as hanging out, entertaining others, visiting, doing homework, going for a walk or a hike, shopping, etcetera. As the Spanish children with CP attend regular schools

this allows them more free time to take part in such activities. Indeed, in the SPARCLE study children in special schools or special classes participated less frequently in activities as eating out, shopping, playing sports and watching sport events compared with children in regular schools (Michelsen et al., 2009).

At the same time, the type of school may have been a confounding variable, the question whether there were differences among children attending regular school and special school in the two countries could not be assessed due to the fact of the small sample size and the small variation within the groups in each country. Palisano et al. (2009) found that youths with CP in regular school were more likely to engage in activities with their friends than those in special educational programs. Likewise, Italian parents believed that their children's integration in mainstream school was important to facilitate social interactions (McManus et al., 2006).

In order to enhance our understanding of the differences in diversity of participation in leisure activities between children and adolescents with and without CP in Spain and The Netherlands, we examined the 20 activities that most children and adolescents participated in. The results showed differences in patterns between Spanish and Dutch children and adolescents, regardless of the presence of CP. Some of these differences in participation between the Spanish and Dutch sample seem to reflect culturally determined patterns. For example, while 80% of the sample with CP in The Netherlands participate in the Dutch traditional activity of bicycling, only 34.2% of the Spanish children and adolescents with CP reported taking part in this activity. One study has shown that school-aged children in Ireland and England are more often physically active than children in Italy, France and Germany (Currie, 2004), and results of the SPARCLE study indicated that the frequency of children riding a bike was the highest in countries where there is a tradition of bicycling, such as Denmark and Germany (Michelsen et al., 2009). In analogy to the bicycling example, Spanish children and adolescents in the present study more frequently reported 'hanging out' as a favorite activity probably due to the fact that this leisure activity is very traditional in Spain. The results of a Canadian study showed that between 30% and 50% of the children with CP participated in bicycling, at least weekly, while, more than 50% of children with CP participated in hanging out (Majnemer et al., 2008). Interestingly, none of the two activities appeared in the 20 activities that most children participated in, in an Australian study which included 114 children with CP, aged between 10 years 9 months and 12 years 9 months (Imms et al., 2008).

However, there are activities that seem to be free from country differences, such as watching TV and talking on the phone, in which the results between both countries were similar in both

the group of children with CP, as well as in the reference group. Watching TV was the main activity carried out by the Dutch children with CP and ranked second for the Spanish children with CP. This was true in other international studies (Canada and Australia) where watching TV ranked first in all activities of CAPE (Imms et al., 2008; Law et al., 2006).

In order to get more insight in the participation of children with disabilities, a key point is the identification of its determinants. Information gathered on determinants of participation might be helpful to assist families and professionals to guide health promotion strategies and policies aiming to optimize the involvement of children in activities at home, school and community. Also, knowledge of activities the child enjoys and family activity orientation has implications for identifying opportunities for participation (Palisano et al., 2009).

The full regression model including child variables in the present study explained 14% of the variance in scores of overall diversity and intensity, and 28% in diversity in recreational and 22% in active physical activities. This rather low level of explained variance supports previous studies that have shown that participation is complex and multidimensional (King et al., 2007; Palisano et al., 2009). The total of unexplained variance could be due to the fact that we were only able to control for environmental variables country and type of school. We agree, therefore, with recent calls in the literature to encourage researchers and rehabilitation professionals to consider environmental factors while assessing child participation (Rosenberg, Ratzon, Jarus, & Bart, 2011).

Not surprisingly, in the present study level of motor function of the child was the variable related to various activity types across the CAPE diversity and intensity scores. Findings of previous studies show that participation of children with CP differs based on their gross motor function (Bult, Verschuren, Jongmans, Lindeman, & Ketelaar, 2011; Imms et al., 2008; King et al., 2007; Majnemer et al., 2008; Orlin et al., 2010; Palisano et al., 2009). Parkes, McCullough and Madden (2010) reported that gross motor function was a major determinant of participation in eight out of 11 domains of the Life-H questionnaire where increasing severity of impairment was related to a significantly reduced likelihood of high participation among children with CP in Ireland. In addition, intellectual level has been reported to be a determinant of participation of children with CP (Bult et al., 2011; Majnemer et al., 2008). However, we were unable to confirm this finding in our study, possibly because the limited sample size or limited variance within the scores.

Unfortunately, one of the main limitations of our study is that some variables considered important predictors of participation such as environmental and family variables could not be assessed because of the nature of the samples derived from the CAPE validation study in

Spain and The Netherlands. Moreover, the different numbers of children in CP groups, and the differences found regarding the type of school and GMFCS levels between children in the two countries also may have affected the results. These factors should be considered in future research.

The strength of our study is that it is the first to compare the participation of two European samples of children and adolescents with and without CP utilizing the CAPE as measurement instrument, having carefully considered it to be the most appropriate tool to evaluate participation. Coinciding with this argument, The SPARCLE group recommends the use of the CAPE, which captures, among other aspects, frequency rather than difficulty of participation and does not incorporate assistance needed into the scoring system, as for example, the Life-H questionnaire (Fauconnier et al., 2009).

The findings of this study highlight that children and adolescents with CP who live in Spain and The Netherlands present similarities and differences in their participation in leisure activities. The differences can be partly accounted for by country specific aspects and partially by variables related to the child's disability. The findings in the reference group confirm the differences between Spain and the Netherlands. In conclusion, this study describes the participation of Spanish and Dutch children and adolescents with CP and with typical developing, contributing to the effort of broadening our knowledge about the participation, their patterns of results in children and adolescents with CP, valuing cross cultural studies.

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Chapter 7

Do children participate in the activities they prefer?

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ABSTRACT

Objectives: Preference for activities has been identified as an important determinant of participation in leisure activities. The aim of this study is to explore the discrepancy between the leisure activities children prefer and the leisure activities they actually participate in, for children with and without a physical disability, and to explore how in both groups this is related to age and gender.

Subjects: : 141children (6-18 yrs) with a physical disability (mean age 12.5, 42.6% girls, 57.4% boys) and 156 children without physical disabilities (mean age 11.5, 54.5% girls, 45.5% boys) completed the Children's Assessment of Participation and Enjoyment (CAPE) and the Preferences for Activities of Children (PAC). A discrepancy score was calculated representing high preference but no participation in the activity in the past 4 months.

Results: There was no significant difference in discrepancy scores between children with and without physical disabilities. Discrepancy between preference and performance varied by age and gender for children without disabilities but not for children with disabilities.

Conclusions: Although children with physical disabilities are known to participate in a significantly lower number of activities there does not seem to be a larger discrepancy between their preference and actual performance compared to children without disabilities. Given this surprising finding, more research is needed to identify determinants of this discrepancy.

INTRODUCTION

Participating in activities contributes to an individual's physical and social well-being and is a determinant of quality of life (Dahan-Oliel, Shikako-Thomas, & Majnemer, 2011; Heah, Case, McGuire, & Law, 2007; Mc Manus, Corcoran, & Perry, 2008). For children and adolescents participation in leisure activities is vitally important for the development of skills, engaging in social contact, exploring personal interests and enjoying life (King et al., 2003; Simpkins, Ripke, Huston, & Eccles, 2005). Leisure activities are defined as 'freely chosen activities performed when not involved in self-care or (school)work' (King et al., 2003).

Participation in leisure activities is often challenged for children and adolescents with physical disabilities. Their participation is less frequent and they participate in fewer activities, because of multiple reasons related to environmental and personal factors (Bult et al., 2010; Calley et al., 2011; Engel-Yeger & Hanna Kasis, 2010; Imms, Reilly, Carlin, & Dodd, 2008). Identified environmental factors are family income (King et al., 2009; Law et al., 2006), family participation (King et al., 2006) and policies in the environment (King et al., 2009). Most often associated personal factors correlated with participation are age (Klaas, Kelly, Gorzkowski, Homko, & Vogel, 2010; Maher, Williams, Olds, & Lane, 2007; Majnemer et al., 2008; Morris, Kurinczuk,

Fitzpatrick, & Rosenbaum, 2006), gender (Imms, Reilly, Carlin, & Dodd, 2009; King et al., 2009; Klaas et al., 2010; Mc Manus et al., 2008) and preference for activities (Imms et al., 2009; King et al., 2009). Preference refers to what a child would like to do.

Preferences for activities are a result of the beliefs and values of the people in the social environment of the child, success of earlier experiences of children and the level of enjoyment the child encountered doing activities (Larson & Verma 1999; Simpkins et al., 2005; Watkinson, Dwyer & Nielsen, 2005).Currently very few studies have looked into the relation between preference of children and the activities they actually engage in. For children without physical disabilities one study has shown that there is a significant relation between the preference of children and the activities they do (Garton & Pratt 1991). A study focussing on children with cerebral palsy (CP) (Majnemer et al., 2010) investigated the relation between preference scores and actual engagement in preferred activities. They reported only moderate relations overall and one specific significant relation for recreational and skill-based activities. Another study reported that preference and actual activities of children with learning disabilities showed no correlation at all (Yalon-Chamovitz, Mano, Jarus & Weinblatt, 2006).

Preference for activities differs as a result of gender and age (Larson & Verma, 1999; Simpkins et al., 2005). One study described that boys tend to prefer sports and gaming activities where girls prefer more social- and skill-based activities (Cherney & London, 2006). Differences in preference between boys and girls already exist from an early age. Boys and girls at the age of two already have gender specific preferences for toys and show different play behaviour (Campbell, & Caygill, 2002). Boys tend to prefer more active play, while girls prefer social play together with friends (Campbell, Shirley & Caygill, 2002; Saint-Maurice, Welk, Silva, Siahpush, & Huberty, 2011). School-aged children tend to have higher preference for physical activities and informal activities whereas older children are more likely to prefer skill-based activities and self-improvement activities (Engel-Yeger, 2011).

A variety in preference could lead to a variety in discrepancy between what children without physical disabilities want and what they actually do. Younger children could have a greater discrepancy because they have less experience in what is practically feasible. Discrepancy for boys and girls could differ between activity types as a result of different preference and not being able to participate in all preferred activities. Children with physical disabilities face challenges and barriers as a consequence of their activity limitations. Because of that it could very well be that they come across activities they would want to do but do not engage in. Not being able to do the activities children prefer could have negative psychological consequences like feeling alone and depressed (Cadman, Boyle, Szatmari, & Offord, 1987).

Being able to choose which activities a child wants to engage in according to his or her own preference is most satisfying and contributes greatly to quality of life and is beneficial for all children (Dahan-Oliel et al., 2011; Shikako-Thomas et al., 2009). To date no studies are available that have looked at the discrepancy between which activities children prefer and their engagement in the activity even though it is clear that not being able to participate in preferred activities has negative consequences. As a result the discrepancy between preference and performance is a very valuable way of looking at participation of children and youth. Therefore the aim of this study is 1) to assess whether there is a discrepancy between the leisure activities children prefer and the leisure activities they actually participate in, for children with and without a physical disability, in different activity types, and 2) to explore if in both groups discrepancy scores between preference and performance for participation in leisure activities differ with age and gender.

METHODS

The data were gathered as part of a validation study of the Dutch Children's Assessment of Participation and Enjoyment (CAPE) (Bult et al., 2010) and the DiPart-CY (Disability and Participation – Children and Youth) study. The diagnoses of physical disability were categorized by a rehabilitation physician (see Table 7.1). This convenience sample was taken from two schools for special education for children with physical disabilities, and from two organizations that counsel children with disabilities who attended regular school classes in their community. Children were eligible if they were aged between 6 and 18 years and able to complete the CAPE with or without assistance. After approval of the ethics committee of University Medical Centre Utrecht and the local school management, parents were sent an information letter about the study, together with a consent form and a stamped return envelop. Parents who returned the informed consent form participated in the study with their child.

Participation

Participation was assessed using the CAPE. The CAPE is a 55-item questionnaire that assesses participation in leisure activities of children and adolescents from 6 to 21 years (King et al., 2007). The CAPE is a self-report measure that has shown to be valid and reliable in the Dutch population (Bult et al., 2010). The CAPE assesses five dimensions of participation; diversity (has the child done the activity in the past four months), intensity (how often has the child done these activities), with whom, where, and enjoyment (how much did the child like or enjoy the

activity). Scores can be calculated for five different activity types (recreational activities, active physical activities, social activities, skill-based activities and self-improvement activities) and two domains (formal and informal activity domain). In this study the diversity scores were used. This is a dichotomous variable (0, the child has not done the activity in the past 4 months; 1 the child has done the activity in the past 4 months). Diversity scores can range according to the number of activities in each activity type; 0-12 for recreational activities, 0-13 for active physical activities, 0-10 for social, skill based and self-improvement activities, 0-15 for formal activities and 0-40 for informal activities.

Preference

Preference was assessed using the Preferences for Activities of Children (PAC). The PAC (King et al., 2007) is a questionnaire that assesses the preference for activities. This measures accompanies the CAPE and assesses preference on a 3 point scale (1 = Would not like to do at all, 2 = Would sort of like to do, 3 = Would really like to do) for the same 55 activities as mentioned in the CAPE.

Procedure

Data were collected by 15 research assistants, who received a training in administration of the measures. The CAPE and PAC were completed in a one-on-one session with one of the research assistants. Assistance was provided by the research assistant through explaining the purpose of the measures, explaining the answers that could be given and giving examples to the child whenever an activity was unclear. Demographic data, age and gender, were gathered through the informed consent form filled out by the parents.

Data analysis

To analyse the discrepancy between the participation and preference scores an item-discrepancy score was calculated. This item discrepancy score represents the number of activities the child would like to engage in but has not engaged in 4 months prior to the assessments. First the PAC preference scores of each item were dichotomized indicating that the child did 'would not like to do at all' (score 0), or 'would sort of like to do it' and 'would really like to do it (score 1).

The diversity score of the CAPE and the dichotomized score of the PAC were combined resulting in a 'discrepancy score'. Whenever a child preferred an activity (dichotomized PAC

score was 1) but the diversity score on the CAPE indicated that the activity was not done in the past 4 months (diversity score 0) the score for discrepancy was 1. All other combinations of participation and preference scores were coded as 0. Thus we focused on the discrepancy for activities the child preferred to do, but has not done in the last 4 months. Discrepancies scores for activities children were engaged in but did not like were not calculated.

Next, discrepancy scores were calculated for each activity type and the formal and informal domains scores by adding up all the scores for the items on a specific activity type. For this discrepancy sum score a higher score indicates a discrepancy on more items in the activity type.

To analyse the difference in discrepancy scores between children with and without disabilities, boys and girls and children (6-12 years of age) and adolescents (13-18 years of age), independent t-tests were used for the five activity types and two domains.

RESULTS

In total 145 children with physical disabilities and 158 children without disabilities were included in the analyses. Four children with disabilities were excluded from the analysis because they had only completed the CAPE or the PAC. From the group of children without disabilities, two were excluded because they only filled out the CAPE and not the PAC. The mean age of the children with a physical disability was 12.5 years (SD 3.3), for children without a physical disability the mean age is 11.5 years (SD 3.1). See Table 7.1 for demographic characteristics.

Table 7.2 shows how many activities the children participated in during the 4 months prior to the assessment and the preferences for these activities for both children with and without physical disabilities. Children with physical disabilities participated in significantly less activities in all activity types both in the formal and informal activity domain. Differences for the preference scores were small but statistically significant. Preference scores were lower for children with physical disabilities on active physical, social activities and informal activities.

Table 7.3 shows the discrepancy scores for the children with and without disabilities at activity type level. There are no significant differences between children with and without disabilities on the discrepancy scores in each activity type nor for the formal and informal domain. A discrepancy score of 2 on 'recreational activities' means that the child expressed a preference for two activities but has not participated in these two activities in the past four 4 months.

Table 7.1 Demographic characteristics

	Total study sample		Children with a physical disability		Children without a physical disability	
	N = 297	%	*N* = 141	47.5%	*N* = 156	52.5%
Gender						
Female	145	43.9	60	42.6	85	54.5
Male	152	46.1	81	57.4	71	45.5
Age (in years)						
6-12	168	50.9	73	51.8	95	60.9
13-18	129	39.1	68	48.2	61	39.1
Diagnoses						
Central nervous system (CNS)						
Acquired brain injury			8	5.7		
Cerebral palsy or related			42	29.8		
Developmental delay			22	15.6		
Minor motor			11	7.8		
Spina bifida, spinal cord or related			13	9.2		
Other CNS			20	14.2		
Musceloskeletal						
Neuromuscular			12	8.5		
Skeletal			10	7.1		
Other musculoskeletal			1	0.7		
Unknown			2	1.4		

Table 7.4 shows that for children with a physical disability only on social activities boys have a higher discrepancy score than girls. For the children without physical disabilities boys also have a significantly higher discrepancy score on social activities, whereas girls have a higher discrepancy score on skill based activities and formal activities.

The same comparison was made based on age. Table 7.5 shows the results of these analyses. There was no difference between children and adolescents with a disability on the discrepancy scores for the activity types or the formal and informal domain. Children and adolescents without disabilities differed significantly on 4 out of 5 activity types and the formal and informal domain: children had higher discrepancy scores for physical activities, social activities and skill based activities and for both the formal and informal domain. Adolescents had higher discrepancy scores for self improvement activities.

Table 7.2 Activity types diversity scores and mean preference score per activity type for children with and without physical disabilities

	Children with a physical disability Diversity sum scores (SD) *N* = 141	Range	Children without disability Diversity sum scores (SD) *N* = 156	Range	*t*-value (df 300)	Children with a physical disability Preference mean scores (SD) *N* = 141	Range	Children without physical disability Preference mean scores (SD) *N* = 156	Range	*t*-value (df 295)
Recreational activities	7.4 (2.4)	1-12	8.0 (2.2)	2-12	2.4*	2.2 (0.4)	1.3-3.0	2.2 (0.4)	1.3-3.0	0.3
Active physical activities	3.1 (1.9)	0-9	4.4 (2.0)	0-9	5.5**	2.0 (0.5)	1.2-3.0	2.2 (0.4)	1.3-2.9	3.8**
Social activities	6.3 (2.0)	1-10	7.2 (2.0)	1-14	4.0**	2.5 (0.3)	1.5-3.0	2.6 (0.3)	1.3-3.0	3.6**
Skill-based activities	1.8 (1.6)	0-8	2.6 (1.6)	0-8	4.6**	2.0 (0.5)	1.0-3.0	2.1 (0.5)	1.0-3.0	1.7
Self-improvement activities	4.1 (1.9)	0-9	4.9 (2.0)	0-9	3.7**	1.7 (0.4)	1.0-2.9	1.7 (0.4)	1.0-2.7	1.2
Informal activities	20.6 (5.8)	6-36	24.1 (4.9)	13-34	5.7**	2.1 (0.3)	1.4-2.9	2.2 (0.3)	1.5-2.8	3.0*
Formal activities	2.4 (1.6)	0-9	3.4 (1.9)	0-11	4.9**	1.9 (0.4)	1.1-2.9	2.0 (0.3)	1.1-2.9	1.9

SD, standard deviation; df, degrees of freedom.
* $p < 0.05$, ** $p < 0.001$

Table 7.3 Preference discrepancy sum scores (number of activities for which participants showed a discrepancy)

	Children with a physical disability Preference discrepancy sum (SD) *N* = 141	Range	Children without physical disability Preference discrepancy sum (SD) *N* = 156	Range	*t*-value (df 295)
Recreational activities	2.0 (1.7)	0-8	1.9 (1.6)	0-6	-0.5
Active physical activities	5.4 (2.5)	0-11	5.8 (2.2)	1-11	1.7
Social activities	2.5 (1.8)	0-8	2.2 (1.7)	0-8	-1.4
Skill-based activities	4.4 (2.6)	0-10	4.4 (2.1)	0-9	0.1
Self-improvement activities	1.9 (1.7)	0-8	2.1 (1.7)	0-9	0.8
Informal activities	9.8 (5.0)	2-23	9.8 (4.6)	1-22	-0.01
Formal activities	6.4 (3.4)	0-15	6.6 (2.8)	0-13	0.6

df, degrees of freedom.

DISCUSSION

This study has demonstrated that there is no difference in the discrepancy between preference and performance in leisure activities between children and adolescents with physical disabilities and their non-disabled peers. However, differences were found for the diversity and preference scores, of which the discrepancy score was derived. Age and gender had a significant effect on the discrepancy scores for children and adolescents without physical disabilities but not for children with physical disabilities.

This is the first study that compared the discrepancy between preference and performance for participation in leisure activities for children with and without physical disabilities. This study has found lower preference for activities for children with physical disabilities. Why they have lower preference for activities remains unclear from these data. However, one earlier study reported that children with Developmental Coordination Disorder (DCD) have lower preference for all types of leisure activities than children without physical disabilities (Engel-Yeger & Hanna Kasis, 2010). Although they did not relate lower preference to actual participation, a higher preference was related to higher self-efficacy. Self efficacy is the evaluation one makes of his/her capacity to perform a task competently (Harter, 1986). Children that have lower levels of self efficacy have shown lower preference for activities

Table 7.4 Discrepancy scores of boys and girls

	Boys with a physical disability Mean preference discrepancy (SD) *N* = 81	Girls with a physical disability Mean preference discrepancy (SD) *N* = 60	*t*-value (df 139)	Boys without a physical disability Mean preference discrepancy (SD) *N* = 71	Girls without a physical disability Mean preference discrepancy (SD) *N* = 85	*t*-value (df 154)
Recreational activities (range 0-12[a])	1.9 (1.5)	2.1 (2.0)	-0.6	2.0 (1.4)	1.8 (1.7)	0.5
Active physical activities (range 0-13[a])	5.6 (2.7)	5.0 (2.2)	1.6	5.9 (2.2)	5.8 (2.2)	0.2
Social activities (range 0-10[a])	2.8 (1.8)	2.2 (1.6)	2.1*	2.6 (1.8)	1.9 (1.6)	2.4*
Skill-based activities (range 0-10[a])	4.3 (2.7)	4.6 (2.4)	-0.8	3.8 (2.1)	5.0 (1.9)	-3.9**
Self-improvement activities (range 0-10[a])	1.7 (1.8)	2.2 (1.6)	-1.5	2.1 (1.7)	2.0 (1.7)	0.2
Informal activities (range 0-40[a])	10.3 (5.4)	9.9 (5.0)	0.4	10.7 (5.0)	9.6 (4.4)	1.4
Formal activities (range 0-15[a])	6.2 (3.6)	6.6 (3.3)	-0.5	5.9 (2.8)	7.3 (2.8)	-3.1*

[a] Theoretical score range for each activity type score. df, degrees of freedom.
* $p < 0.05$, ** $p < 0.01$

Table 7.5 Discrepancy scores for age groups

	6-12 year olds with a physical disability Mean preference discrepancy (SD) *N* = 73	13-18 year olds with a physical disability Mean preference discrepancy (SD) *N* = 68	*t*-value (df 139)	6-12 year olds without a physical disability Mean preference discrepancy (SD) *N* = 95	13-18 year olds without a physical disability Mean preference discrepancy (SD) *N* = 61	*t*-value (df 154)
Recreational activities (range 0-12[a])	2.1 (1.8)	1.9 (1.7)	0.4	1.9 (1.5)	1.9 (1.6)	0.2
Active physical activities (range 0-13[a])	5.4 (2.8)	5.3 (2.1)	0.2	6.4(2.2)	5.0 (1.9)	4.1**
Social activities (range 0-10[a])	2.5 (1.8)	2.6 (1.7)	-0.4	2.8 (1.8)	1.3 (1.1)	6.5**
Skill-based activities (range 0-10[a])	4.7 (2.7)	4.1 (2.3)	1.4	5.0 (2.0)	3.6 (2.0)	4.1**
Self-improvement activities (range 0-10[a])	2.0 (1.8)	1.8 (1.6)	0.6	2.7 (1.8)	3.6 (1.1)	5.9**
Informal activities (range 0-40[a])	10.4 (5.5)	9.8 (4.8)	0.7	11.5 (4.9)	7.7 (3.3)	5.7**
Formal activities (range 0-15[a])	6.5 (3.8)	6.3 (3.1)	0.4	7.5 (2.7)	5.3 (2.7)	4.8**

[a] Theoretical score range for each activity type score. df, degrees of freedom.
* $p < 0.05$, ** $p < 0.01$

(Engel-Yeger & Hanna Kasis, 2010). Lower preference in turn leads to lower participation. This relation is also found in adults with CP showing that 49% of variance in outcome on social participation could be explained by self efficacy (van der Slot et al., 2010). Apart from the psychological consequences of lower levels of participation studies also show that children that have lower preference for physical activities when they are eight years old participate less in these activities when they are sixteen years old. According to Kantooma et al. (2011) this is associated with higher levels of inactivity and lower levels of fitness leading to potential health risk for adolescents.

Age and gender had a significant effect on the discrepancy scores for children without disabilities but not for children and youth with physical disabilities. The discrepancies found for children without disabilities could be expected because preference of children without physical disabilities also varies between boys and girls and younger and older children (Larson &Verma, 1999; Simpkins et al., 2005). Why these differences were not found for children with physical disabilities remains unclear. As described earlier by Watkinson et al. children evaluate past experiences and incorporate their past achievement in the process of choosing new activities (Watkinson, Dwyer, & Nielsen, 2005). If children with physical disabilities do not experience they can be successful in activities it is less likely that they will choose those activities again. Moreover, variables related to the environment the child lives in could be of importance. The beliefs and values of important people around the child, such as the parents, also influence preference of the child. Research shows that family activity preferences influence participation of the child (King et al., 2006). It is also known that a substantial number of parents of young children with CP view themselves as not being able to participate in activities as a normal family. Seventy-five percent feels they are partly or completely restricted because they have a child with a physical disability (Rentinck, Gorter, Ketelaar, Lindeman, & Jongmans, 2009). Having few experiences or less positive experiences with participating in leisure activities may lead to negative interpretation of past events and therefore lower preference for activities.

Garton & Pratt (1991) have looked into the discrepancy between preference and performance in adolescents without physical disabilities. Activities for which they have found a discrepancy between preference and performance mainly concerned organized sports that require specific gear or instructions (e.g. horse riding, cricket, water skiing). Reasons for not being able to engage in those activities were the lack of facilities, too much cost involved, people could not get to facilities and the lack of specific gear. The PAC, used in the present study, is not originally designed for the use of single items. However, asking children which activities they would like to do but actually do not do at the moment, and which barriers they encounter in

trying to participate, would be a great contribution to goal setting and interventions aimed at facilitating participation of children with physical disabilities. Attention for the discrepancy could also help in the dialogue with parents and children about the goals they set rehabilitation intervention.

Although this study has given useful insight into the discrepancy between preference and performance there are some limitations. Participation is assessed using the CAPE, which asks for participation in the 4 months prior to the assessment. The PAC assesses preference for activities by asking what the child would like to do. Due to the difference in timeframe there will possibly be a discrepancy between preference and performance. It would be interesting to see if the performance in leisure activities changes over time according to the preferences of the child. In other words, do children have the opportunity to express their preference and wishes and is their an increase in the performance in these activities accordingly?

Further research into child characteristics related to the development of preference in children with a physical disability is needed. Since the development of preference depends on earlier experiences of the child including those of the social environment, future research should incorporate those factors as well. Focusing on the participation of families and supporting parents to engage in all kinds of activities with their child(ren) to foster positive leisure experiences in children with physical disabilities is therefore crucial.

This article has shown significantly lower preferences for activities of children with physical disabilities. Even though this may not lead to a higher discrepancy between the activities they actually engage in, lower preference at itself is an important finding. Children with physical disability might 'settle for less' estimating that many activities might be hard for them to engage in. Rehabilitation intervention should therefore not only try to focus on functional limitations and promoting participation but also focus on the dreams and expectations of children, trying to broaden the horizon encouraging them to have dreams and making plans to achieve them, even though they might think they are unreachable.

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Chapter 8

Summary and general discussion

The aim of my thesis was to describe participation in leisure activities of children and youth aged 2 to 18 years with and without a physical disability in the Netherlands and to identify determinants of participation. Although there has been a growing body of literature into participation and determinants of participation, comparisons between children with and without physical disabilities are lacking. Participation is defined as 'involvement in life situations' (World Health Organization, 2001). A range of different determinants are related to participation. These can be related to the child, family or the environment. Because environmental factors differ per country, country specific information is needed. Since the introduction of the International Classification of Functioning (ICF), participation has been more clearly defined enabling measures to be developed and research into determinants to expand. In keeping with my thesis the topics that were investigated were measurement of participation for preschool children, school-aged children and adolescents and determinants related to participation, in a national and international perspective.

First a summary of the main findings of this thesis is given. Subsequently clinical implications and methodological aspects are outlined. Finally, unanswered questions and directions for future research are presented.

Main findings

In **chapter 2** we examined the validity and reliability of the Dutch translation of a measure of participation for preschool children, the Assessment of Preschool Children's Participation (APCP). Construct validity was assessed by means of a number of specific hypotheses, which were confirmed. Participation at preschool age is lower for children with a physical disability (compared to their healthy peers) and for younger children (2-3 years compared to 4-5 years). As expected no differences were found between boys and girls at this young age, except for frequency of skill based activities. Test-retest reliability of the APCP was good to excellent (ICCs .63 - .91). It is concluded that the Dutch APCP is a valid and reliable measure of preschool participation in leisure activities.

Chapter 3 describes the validity and reliability of the Dutch translation of the Children's Assessment of Participation and Enjoyment (CAPE). This is a measure used for assessing participation in children and adolescents aged 6 to 18 years of age, both with and without physical disabilities. Construct validity and both inter-interviewer and test-retest reliability were assessed. Children and adolescents with a physical disability participated with lower intensity than their healthy peers. Differences were found for boys and girls and for school-aged children and adolescents. Boys participated more in physical activities whilst girls participated

more in the other activity types. Adolescents participated more in physical, social and skill-based activities compared to younger children. Participation was found to be related to child (cognition, communicative, physical and social functioning) and family variables (recreational and intellectual cultural orientation). Both inter-interviewer and test-retest reliability were good to excellent (ICCs .61-.83). The CAPE was shown to be a valid and reliable measure of participation in leisure activities.

A review of recent research findings assessing determinants of participation of children and youth with a physical disability aged 2 to 18 years are described in **chapter 4**. Studies looking at different diagnoses were assessed showing similar variables to be related across different diagnostic groups. Most important variables related to participation in leisure activities are gross motor function, manual ability, cognitive ability, communicative skills, age and gender. Related variables are comparable across diagnostic groups.

A prospective study looking at early determinants of participation in children with Cerebral Palsy (CP) is described in **chapter 5**. When the children were 2 years of age an extensive assessment provided data about the child, family and environment of the child. When the child was 6-8 years of age parents filled out the CAPE indicating their child's participation. Multivariate analysis showed movement ability to be the strongest predictor for formal activities and movement ability together with social skills to be the best predictors for informal activities. The regression model looking solely at family variables showed that the feeling of being restricted in family participation at age 2 was the strongest predictor of later participation intensity for both formal and informal activities.

In **chapter 6** participation of Spanish and Dutch children with CP and their non-disabled peers were compared. Spanish children with CP showed more participation in formal activities and skill-based activities compared to Dutch peers. Looking at determinants of variance in participation between children, regression analyses showed that child related variables (age, gender, GMFCS) were related to participation in leisure activities. Country of residence was only related for participation in formal activities. **Chapter 7** describes the relation between preference for activities and actual engagement in activities. Children with a physical disability have lower preference for physical activities, social activities and informal activities compared to their healthy peers. Children with physical disabilities also participate in fewer activities. A discrepancy score was calculated indicating high preference for activities but no participation in the 4 months prior to the assessment. No differences were found for the discrepancy score between children and youth with physical disabilities and their non-disabled peers. Discrepancy scores were influenced by age and gender for children without a physical disability but not for children with a physical disability.

Main findings from this thesis

- The APCP is a valid and reliable measure of participation in preschool children with and without physical disabilities
- The CAPE is a valid and reliable measure of participation in children and adolescents both with and without physical disabilities.
- A wide range of variables are related to participation of children and youth with physical disabilities. Variables are comparable across diagnostic groups
- Already at a young age gross motor function, social skills and the feeling of the parents that they can participate as a regular family is predictive of later intensity of participation in leisure activities.
- When comparing participation of children with CP and their healthy peers across countries differences seem to be culturally determined.
- Children with a physical disability have equal discrepancy scores between the activities they would want to participate in and the activities they actually participate in. Children with physical disabilities have lower preference for all activity types.

Clinical implications

Research has shown that participation has a positive effect on physical and emotional well-being of children and youth with physical disabilities (Dahan-Oliel, Shikako-Thomas, & Majnemer, 2011). Moreover parents and children feel that participation in community life, including leisure, is among the most important outcomes of intervention (Vargus-Adams & Martin, 2010). Participation is one of the major outcomes for rehabilitation programmes (Gorter, 2009). My thesis has shown that valid and reliable participation measures are available to assess leisure participation of children aged 2 to 18 years. Being able to deliver an intervention that is aimed at promoting participation, setting the right reachable and measurable goals is important for several reasons. Interdisciplinary team work will benefit from clear set goals because all team members will be able to work on the shared goals for their own discipline. Moreover achieving a goal gives a feeling of satisfaction for the child, parents and the team (Darrah, Wiart, Magill-Evans, Ray, & Andersen, 2012; Schut & Stam, 1994). Rehabilitation intervention has a main focus on promoting participation. However, evidence based interventions specifically aimed at promoting participation in leisure activities are lacking at the moment. Designing specific interventions for participation can be challenging

because more participation is not necessarily better. Aim of an intervention could also be that children participate in activities more often with friends instead of within the family context, participate more in the community instead of within their home environment or enjoy activities more. Part of the definition of leisure activities states that these activities should be 'freely chosen' by the individual (King et al., 2003). Choice is something very personal and therefore not related to predetermined norms. Qualitative research has shown that successful participation to children means being with others, having fun and doing things independently from others (Heah, Case, McGuire, & Law, 2007).

Although it is known that children with physical disabilities enjoy the same activities as children without physical disabilities their preference for activities is different (Engel-Yeger & Hanna Kasis, 2010; Heah et al., 2007). Preference for activities tends be lower for children with physical disabilities compared to children without physical disabilities. For the school-aged and adolescent children a measure of preference for activities (PAC) is available (King et al., 2007). Preference appears to be an important predictor for participation in activities (Buffart et al., 2008; Imms, Reilly, Carlin, & Dodd, 2009; King et al., 2006). Knowing the child's preference for activities enables clinicians to tailor their intervention doing activities the child likes and setting goals that are relevant and motivating. The PAC is a useful tool to get insight into the activities the child would like to do. In the PAC the child can indicate how much they would like doing an activity if they could choose anything they wanted. The activities in the PAC are the same activities as in the CAPE enabling a thorough assessment of both actual participation as well as preference of the child.

My thesis has shown that already at a young age predictors of later participation can be identified. Moreover it is known that participation patterns remain stable over time (Findlay, Garner, & Kohen, 2009; Findlay, Garner, & Kohen, 2010). Being less active in activities through childhood will probably lead to inactivity in adult life. Attention for the activities young children do, mostly in the context of their families, is important. Research has shown that starting from a young age, children with physical disabilities participate less than their peers without disabilities (Kemps, Siebes, Gorter, Ketelaar, & Jongmans, 2010; Law, King, Petrenchik, Kertoy, & Anaby, 2012; Rosenberg, Jarus, & Bart, 2010). In the early years children are dependent on their parents and participate together with them. Aiming an intervention just at the children is therefore not effective enough. Identifying barriers that parents encounter is an important starting point for promoting participation. Parents of children with physical disabilities feel more fearful and feel there is more risk involved when taking their child to community places. As a result, these parents participate in less community activities than parents of children without physical disabilities (Ehrmann, Aeschleman, & Svanum, 1995). A positive attitude and learning

effective coping strategies will possibly help parents to overcome barriers that are present in the environment (Boucher, Dumas, Maltais, & Richards, 2010).

Methodological aspects

Participation is 'someone's involvement in life situations' and is therefore always happening within a certain context (World Health Organization, 2001). Knowing more about the specific barriers and facilitators in the environment is therefore important. In this thesis information on the environment of the child was gathered on different levels. Both the direct environment (e.g. family characteristics) as well as the more distant environment were captured (e.g. type of daycare, social economics status, facilities nearby). However, no strong relations were found between those environmental variables and participation in leisure activities. One reason might be that the governmental databases used in this research to assess social economic status and facilities nearby, make use of the families' zipp code as a tool to capture the environment (Knol, 1998; Steenbekkers, Simon, & Veldheer, 2006). These zipp codes might not have been sensitive enough to estimate the individual characteristics of the environment of the child in relation to participation. Individualized measures that capture the environment of the child have become available recently. The European Child Environment Questionnaire (ECEQ) is an example of such a measure covering the 'physical, social and attitudinal environmental features likely to be needed by the child' (Colver et al., 2011). Another newly available measure is the Participation and Environment Measure for Children and Youth (PEM-CY) (Coster et al., 2011). This measure 'examines the extent to which young people with and without disabilities participate in important activity areas … also examines the extent to which particular features of the home, school, or community environment are perceived by the parent to be supporting or challenging' (Coster et al., 2011). The use of the PEM-CY encourages professionals involved in care for children with physical disabilities and their parents to identify environmental factors related to the participation of the child in a direct way. Talking to parents about identified barriers is simplified hereby, making it easier to provide help to overcome these barriers.

Another limitation of this thesis can be found in the prospective study described in chapter 5. In this study parents of children with CP that were seen at age 2 were asked to fill out the CAPE when the child was school-aged (6-8 years of age). From the total sample of parents that were asked, a little over half provided this information. Although the children of which no participation data were available did not differ from the group of children that data were available for considering age, gender and GFMCS level, we do not know in which activities they are participating. It could be that the parents experience a higher burden taking care of their child, or the child has additional health or behaviour problems that caused the drop-out

of the study or the follow-up. Possibly they were the ones experiencing most participation problems. If they were included possibly more or other variables could have appeared to be related to participation.

Unanswered questions & future research

My thesis has focussed on differences between children with and without physical disabilities and their participation in leisure activities. Many variables are related to participation in leisure activities, one could be the educational system in the Netherlands. In this thesis no attention has been dedicated to the differences between participation of children within special or regular education. What effect education may have on participation in leisure activities is not known. It is very well possible that those children that go to regular schools have more opportunities to participate in after school activities together with their peers without physical disabilities. Compared to other European countries the Netherlands has by far the highest percentage of children with special educational needs going to schools for special education (62%). In for example the Scandinavian countries only 4% of children are included in special educational settings (European Agency for Development in Special Needs Education, 2010). One of the benefits of special education is that the children receive therapeutic treatment during school hours (e.g. physio-, occupational and speech and language therapy). However research has shown that the time designated for therapy cuts back on the hours for education in other subjects like mathematics, which has in turn a negative effect on skills of these children (Jenks, de Moor, van Lieshout, & Withagen, 2010). Another disadvantage is that the schools for special education are often further away from the homes of the children than regular schools. This means that a substantial part of the time for leisure is dedicated to transportation to and from school. Playing outside with other children in the neighbourhood is often challenging because of the lack of time. Qualitative research has shown that practical barriers and lack of nearby facilities have a negative effect on participation in leisure activities (Verschuren, Wiart, Hermans, & Ketelaar, 2012). Possibly one of the effects of not being able to naturally engage in the after school activities of children without physical disabilities is the shortage of so called 'tacit knowledge' of the children with a physical disability. Tacit knowledge refers to the knowledge that is not taught in school or can be explained in words. It is implicit knowledge that is learned through experience. Tacit knowledge was first introduced by Michael Polanyi in 1958 in the world of philosophy, later described in social sciences as well (Wagner & Sternebrg, 1985). Research suggests that children with a physical disability in countries that are included in regular schools participate in more activities and do so more often (Longo, 2012; Ullenhag, 2012). Perhaps these children have been able to experience how to engage in activities with others in a natural

way and have more tacit knowledge than children that do not engage in these activities from an early age. Future research into personal factors as social skills should give more insight in the ways children interact with each other. In the Netherlands substantial changes will be made in the educational system in the coming years. All schools for regular education are by law obliged to provide education for children with special needs. This legislation holds promising changes but also has an unknown side. Time will tell whether children with physical disabilities will be fully included into regular classes or whether a school conglomerate will provide special classes, clustering special needs pupils preventing full inclusion has effect. Future research on the new educational system should illustrate the advantages and disadvantages.

In the past few years several articles have been written dedicated to measuring participation (Dijkers, 2010; Simeonsson et al., 2003). In the CAPE diversity, frequency, with whom, where and the enjoyment of participation can be assessed. The PAC assesses preference for activities. Although both measures allow an extensive assessment of the child's participation some aspects are still underexposed. Qualitative research has shown that for children and youth successful participation is related to free choice, feeling successful and doing things by themselves (Heah et al., 2007). These aspects are not considered in the CAPE or PAC, neither are these aspects highlighted by the definition of participation in the ICF. The description "Involvement in life situations" does not highlight all the highly valued aspects children and youth call for. Future research should therefore also specify what 'involvement in life situations' is and work on representing al dimensions of participation (e.g. free choice, full inclusion, independence).

Considering the importance of the family environment and the finding that participation patterns are different from an early age future research should focus more on young children with physical disabilities than the school-aged and adolescent children. Research aimed at family interaction, family coping and the use of resources by the family (both financial and social) should receive more attention.

Intervention research should be aimed at optimal participation of the family and child. If the child likes to be engaged in more activities but with lower frequency this should be the starting point of the intervention. If the parents of the child would benefit from the child being more independent this could also be the starting point. In the coming years research will be faced with the challenge of incorporating this individual variance in order to produce knowledge that will help a large group of children and their families in participating in leisure activities.

The above mentioned areas should not only be studied in a quantitative way but also emphasize the personal opinion and feeling of those who are involved. Qualitative research could be a very useful tool to find out more about the variety in participation. Some children with a lot

of functional restrictions do participate in a wide variety of activities. Studies have shown that for example educational level of the parents and family income are related to participation (Klaas, Kelly, Gorzkowski, Homko, & Vogel, 2010; Law et al., 2006). Whether these are related because of a different lifestyle of parents or simply the better financial opportunities remains unclear. More over when planning research (both descriptive studies as well as intervention studies) parents and children should be more actively involved (Jeglinsky, Autti-Ramo, & Brogren Carlberg, 2012; O'neil & Palisano, 2000). Children are experts on their own life, parents are experts on their family life. Together they can provide the knowledge so needed to focus research and to tailor interventions.

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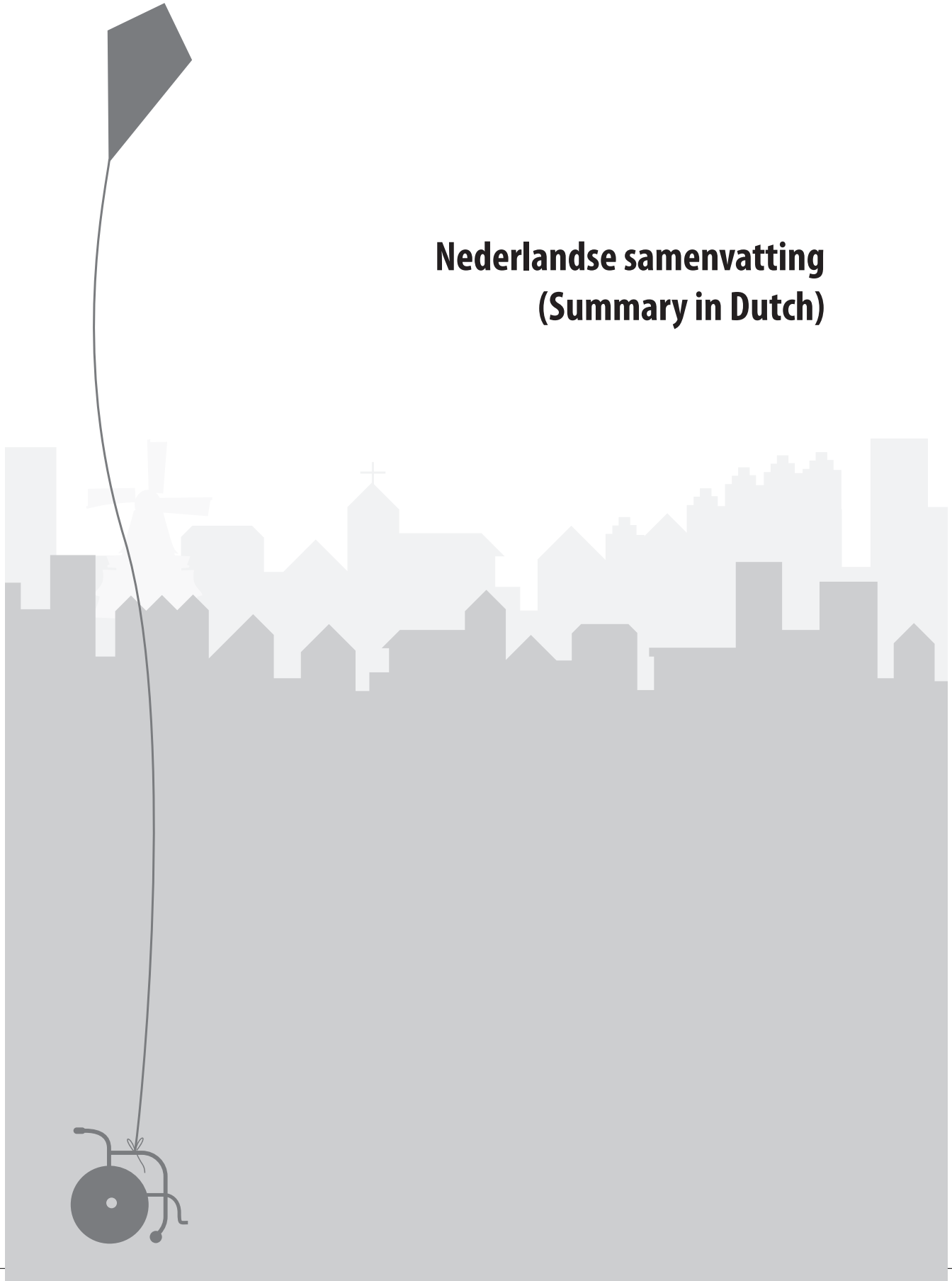
Nederlandse samenvatting (Summary in Dutch)



Het doel van dit proefschrift was om de participatie aan vrijetijdsactiviteiten van kinderen en jongeren van 2 tot 18 jaar met en zonder een lichamelijke beperking in Nederland te beschrijven en determinanten van participatie te identificeren. Participatie wordt door de Wereldgezondheidsorganisatie gedefinieerd in de International Classification of Functioning (ICF) als 'iemands deelname aan het maatschappelijke leven'. Deelname aan vrijetijdsactiviteiten is een belangrijk onderdeel van het maatschappelijk leven van kinderen en jongeren. Hoewel er een groeiende hoeveelheid literatuur over participatie en de determinanten van participatie is, ontbreken er goede vergelijkingen tussen kinderen met en zonder lichamelijke beperking. Sinds de introductie van de ICF is participatie duidelijker gedefinieerd waardoor de ontwikkeling van meetinstrumenten uitgebreid kon worden en onderzoek naar determinanten kon groeien. In dit proefschrift worden meetinstrumenten van participatie aan vrijetijdsactiviteiten voor peuters en kleuters, schoolgaande kinderen en adolescenten onderzocht op methodologische kwaliteit. Vervolgens worden de determinanten die gerelateerd zijn aan participatie aan vrijetijdsactiviteiten van kinderen en jongeren met en zonder beperking, in een nationaal en internationaal perspectief beschreven. In deze samenvatting worden de belangrijkste bevindingen uit het proefschrift besproken.

Belangrijkste bevindingen

In **hoofdstuk 2** werd gekeken naar de validiteit en betrouwbaarheid van de Nederlandse vertaling van een meetinstrument voor het meten van participatie van kinderen in de leeftijd van 2 tot 6 jaar, de Assessment of Preschool 'Children's Participation (APCP). De constructvaliditeit werd vastgesteld door middel van een aantal specifieke hypothesen, welke zijn bevestigd. De participatie in activiteiten is lager voor kinderen met een lichamelijke beperking (in vergelijking met hun gezonde leeftijdgenoten) en voor jongere kinderen (2-3 jaar ten opzichte van 4-5 jaar). Zoals verwacht werden geen verschillen gevonden tussen jongens en meisjes op jonge leeftijd, met uitzondering van de frequentie van activiteiten waar vaardigheden voor nodig zijn (bijvoorbeeld puzzelen, luisteren naar verhalen). De test-hertestbetrouwbaarheid van het APCP was goed tot uitstekend (ICC's 0.63 tot 0.91). De conclusie is dat de Nederlandse vertaling van de APCP een valide en betrouwbaar meetinstrument is voor het meten van participatie in vrijetijdsactiviteiten voor kinderen in de leeftijd van 2 tot 6 jaar.

Hoofdstuk 3 beschrijft de validiteit en betrouwbaarheid van de Nederlandse vertaling van de Children's Assessment of Participation and Enjoyment (CAPE). Dit instrument meet participatie in vrijetijdsactiviteiten bij kinderen en jongeren van 6 tot 18 jaar, zowel met als zonder lichamelijke beperking. De constructvaliditeit werd bepaald aan de hand van een aantal hypothesen, welke grotendeels konden worden bevestigd. Kinderen en jongeren met een lichamelijke

beperking participeren met een lagere intensiteit dan hun gezonde leeftijdgenoten. Verschillen werden gevonden tussen jongens en meisjes en tussen kinderen in de basisschoolleeftijd en jongeren. Jongens participeren meer in fysieke activiteiten terwijl meisjes meer participeren in de andere activiteitentypes. Adolescenten participeren meer in fysieke en sociale activiteiten en activiteiten waar vaardigheden voor nodig zijn in vergelijking met jongere kinderen. Participatie in vrijetijdsactiviteiten bleek samen te hangen met kind- (cognitie, communicatief, lichamelijk en sociaal functioneren) en gezinsvariabelen (recreatieve en intellectuele culturele oriëntatie). De inter-interviewer- en test-hertestbetrouwbaarheid waren goed tot zeer goed (ICC's 0.61 tot 0.83). Er kon geconcludeerd worden dat ook de Nederlandse versie van de CAPE een valide en betrouwbaar meetinstrument is om participatie in vrijetijdsactiviteiten te kunnen meten.

Recente onderzoeksresultaten die de determinanten van participatie van kinderen en jongeren met een lichamelijke beperking van 2 tot 18 jaar onderzochten, werden beschreven in een literatuurstudie in **hoofdstuk 4**. Voor verschillende diagnostische groepen werden overeenkomstige factoren gevonden die gerelateerd zijn aan de participatie van kinderen en jongeren. De belangrijkste variabelen gerelateerd aan de deelname aan vrijetijdsactiviteiten zijn grove motoriek, manuele vaardigheden, cognitieve vaardigheden, communicatieve vaardigheden, leeftijd en geslacht. Er is relatief weinig informatie bekend over de participatie van jonge kinderen met een lichamelijke beperking.

Een prospectieve studie naar vroege voorspellers van participatie bij kinderen met cerebrale parese (CP) is beschreven in **hoofdstuk 5**. Toen de kinderen 2 jaar oud waren zijn door middel van een uitgebreid onderzoek (PERRIN) gegevens over het kind, het gezin en de omgeving van het kind in kaart gebracht. Toen deze kinderen tussen de 6-8 jaar oud waren hebben ouders de CAPE ingevuld en daarmee gegevens over de participatie van hun kind gedeeld. Multivariate analyse toonde aan dat grof-motorisch functioneren de sterkste voorspeller voor participatie in formele activiteiten (georganiseerde activiteiten met bepaalde regels) en grof-motorisch functioneren samen met sociale vaardigheden de beste voorspellers zijn voor participatie in informele activiteiten (spontane, vaak kindgeïnitieerde activiteiten). Uit het regressiemodel gericht op de gezinsfactoren bleek dat, wanneer ouders het gevoel hebben beperkt te zijn in het ondernemen van dagelijkse gezinsactiviteiten als het kind 2 jaar oud is, dit de sterkste voorspeller was van de intensiteit van de participatie in vrijetijdsactiviteiten van het kind op 6- tot 8-jarige leeftijd in zowel formele als informele activiteiten.

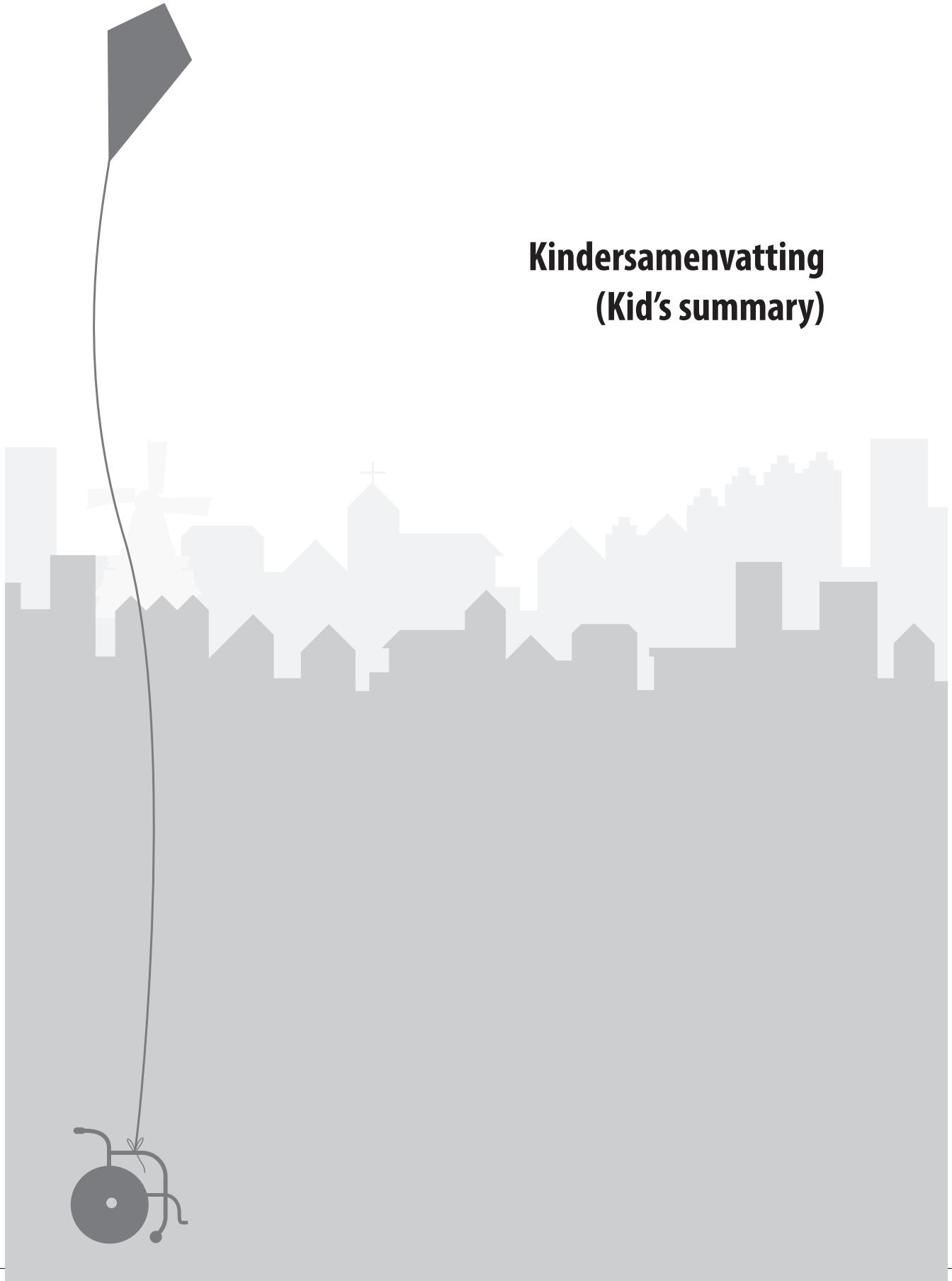
In **hoofdstuk 6** werd de participatie van Spaanse en Nederlandse kinderen met CP en hun gezonde leeftijdgenoten met elkaar vergeleken. In vergelijking met Nederlandse kinderen met CP participeerden Spaanse kinderen met CP meer in formele activiteiten en in activiteiten waar vaardigheden voor nodig zijn (bijvoorbeeld paardrijden, een muziekinstrument spelen). Er zijn

geen verschillen gevonden voor de informele activiteiten. Als we kijken naar determinanten van de verschillen tussen Nederlandse en Spaanse kinderen dan toont regressieanalyse aan dat kindvariabelen (leeftijd, geslacht, niveau van grof-motorisch functioneren) gerelateerd zijn aan de deelname aan vrijetijdsactiviteiten. Het land waar iemand woont was alleen van invloed op de deelname aan formele activiteiten. **Hoofdstuk 7** beschrijft de relatie tussen de voorkeur voor activiteiten in de vrije tijd en de daadwerkelijke participatie in deze activiteiten. Kinderen met een lichamelijke beperking hebben minder voorkeur voor fysieke activiteiten, sociale activiteiten en informele activiteiten in vergelijking met hun gezonde leeftijdgenoten. Zij participeren ook minder in deze activiteiten. Er werd een discrepantiescore berekend die aangaf voor hoeveel activiteiten er een hoge voorkeur is, maar waarin het kind niet heeft geparticipeerd in de afgelopen 4 maanden. Er werden geen verschillen gevonden voor de discrepantiescore tussen kinderen en jongeren met een lichamelijke beperking en hun gezonde leeftijdgenoten. Verschilscores werden beïnvloed door leeftijd en geslacht voor kinderen zonder een lichamelijke beperking, maar niet voor kinderen met een lichamelijke beperking.

Belangrijkste bevindingen uit dit proefschrift

- De APCP is een valide en betrouwbaar meetinstrument voor het meten van participatie in vrijetijdsactiviteiten bij kinderen in de leeftijd van 2 tot 6 jaar met en zonder een lichamelijke beperking.
- De CAPE is een valide en betrouwbaar meetinstrument voor het meten van participatie in vrijetijdsactiviteiten bij kinderen en jongeren met en zonder een lichamelijke beperking in de leeftijd van 6 tot 18 jaar.
- Er is een groot aantal variabelen gerelateerd aan de participatie in vrije tijdsactiviteiten van kinderen en jongeren met een lichamelijke beperking. Variabelen zijn vergelijkbaar tussen diagnostische groepen.
- Grof-motorisch functioneren en sociale vaardigheden van het kind op tweejarige leeftijd en het gevoel van ouders dat zij beperkt zijn in het ondernemen van gezinsactiviteiten als hun kind jong is, zijn gerelateerd aan de intensiteit van deelname aan vrijetijdsactiviteiten van het kind op schoolgaande leeftijd.
- Bij het vergelijken van participatie van kinderen met CP en hun gezonde leeftijdgenoten tussen Nederland en Spanje lijken gevonden verschillen, voor formele activiteiten, cultureel bepaald te zijn.
- Kinderen met een lichamelijke beperking ervaren geen grotere discrepantie tussen de activiteiten waarin zij zouden willen participeren en de activiteiten waarin zij daadwerkelijk participeren in vergelijking met kinderen zonder een lichamelijke beperking. Kinderen met een lichamelijke beperking hebben wel een lagere voorkeur voor alle types van activiteiten.

Kindersamenvatting (Kid's summary)



Waar gaat het over?

Dit boekje gaat over vrije tijd van kinderen en jongeren. Vrije tijd is alle tijd die je na school en in het weekend hebt om leuke dingen te gaan doen. Hierbij kun je denken aan thuis knutselen, sporten, dingen met anderen samen doen of naar muziekles gaan. Het boekje gaat over deze activiteiten omdat het belangrijk en leuk is om dingen te doen in je vrije tijd. Belangrijk omdat je er dingen van kan leren (bijvoorbeeld bij sport of muziekles) en leuk omdat je er meestal vrolijk van wordt. Dit boekje gaat vooral over kinderen die een lichamelijke handicap hebben. Dat zijn kinderen die bijvoorbeeld moeite hebben met lopen, het bewegen van hun armen of praten. Als je minder makkelijk beweegt kan het ook moeilijk zijn om een goede sport te vinden om te doen, of als je in een rolstoel zit kun je soms niet overal naar toe als je dat wil.

Waarom hebben we dit boekje geschreven?

Omdat het voor kinderen met een handicap net zo belangrijk en leuk is om dingen te doen in hun vrije tijd, hebben we onderzocht of zij ook dezelfde dingen kunnen doen in hun vrije tijd als kinderen zonder handicap.

Hoe hebben we dat gedaan?

We hebben een heleboel kinderen gevraagd aan ons te vertellen wat ze doen in hun vrije tijd. Dit hebben we gevraagd aan kinderen met een handicap en zonder handicap. We weten ook veel dingen die hun ouders verteld hebben. Bijvoorbeeld over dingen die moeilijk zijn voor de kinderen om te doen.

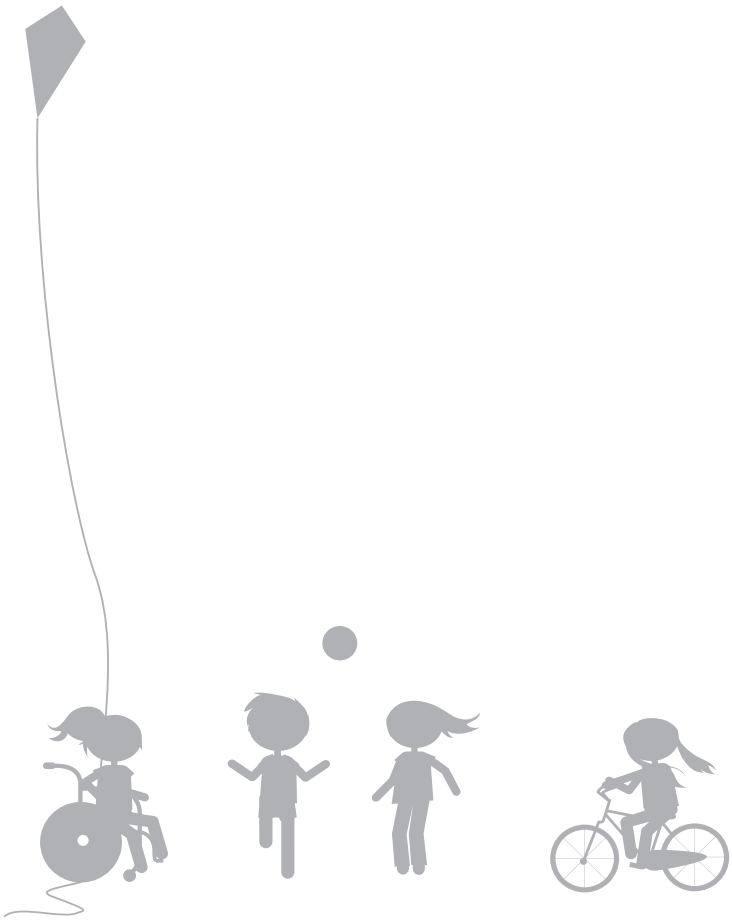
Wat weten we dan nu?

We weten dat kinderen met een handicap best veel dingen doen in hun vrije tijd, maar dat zij dingen minder vaak doen dan kinderen zonder handicap. We hebben niet alleen gekeken naar de verschillen in activiteiten als je een handicap hebt of niet, maar ook naar verschillen tussen jongens en meisjes en jongere en oudere kinderen. Daarom weten we nu ook dat jongens meer sportieve activiteiten doen en meisjes meer activiteiten waar je dingen van leert of creatieve activiteiten. Kinderen op de basisschool doen minder vaak sportieve activiteiten of activiteiten met vrienden dan kinderen op de middelbare school. We weten ook dat best heel veel dingen er samen voor zorgen dat kinderen minder actief zijn in hun vrije tijd. Je kan het probleem

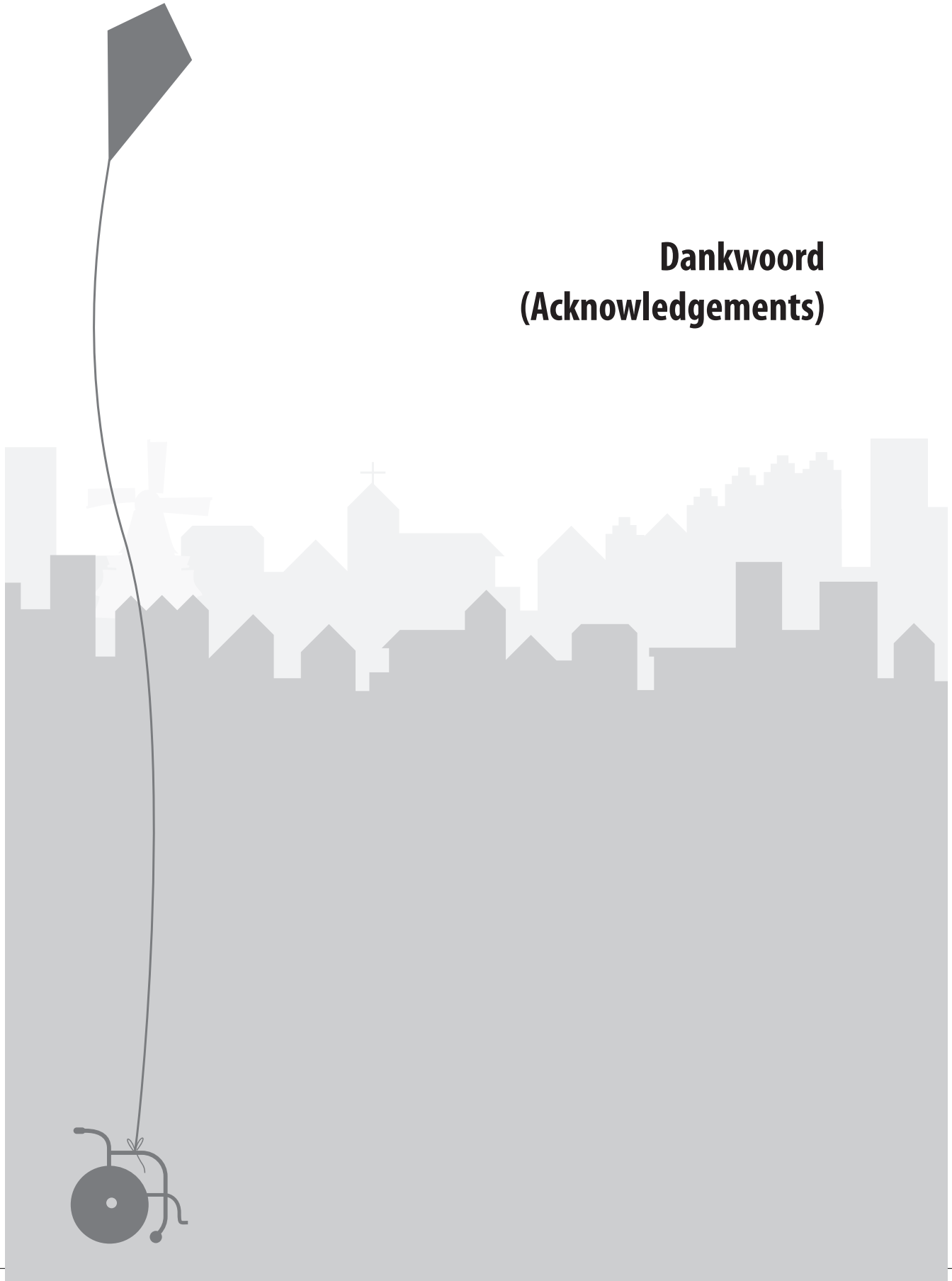
dus niet oplossen door één ding te veranderen. We hebben ook naar andere landen gekeken. We weten nu bijvoorbeeld dat kinderen in Spanje andere activiteiten doen in hun vrije tijd dan Nederlandse kinderen. Dan gaat het over kinderen met een handicap maar ook over kinderen zonder een handicap.

Wat gaan we dan nu doen?

Alle informatie die opgeschreven staat in het boekje gaan we laten lezen aan dokters, fysiotherapeuten en andere mensen die kinderen met een handicap helpen. We hopen dat ze door het lezen van dit boekje een beetje beter weten waarom kinderen met een handicap minder actief zijn en dat ze zo de kinderen die actiever willen zijn daarbij kunnen.



Dankwoord
(Acknowledgements)



What an absolute joy of finally being able to write these acknowledgements to all those people that have been so supportive; professionally, personally and so many both. I am starting these acknowledgements in English because there are some personal words to be written in an international context as well. I feel very blessed to have been surrounded by so many wonderful and inspiring people during my PhD project. Each and everyone of you have contributed to this thesis in your own personal way.

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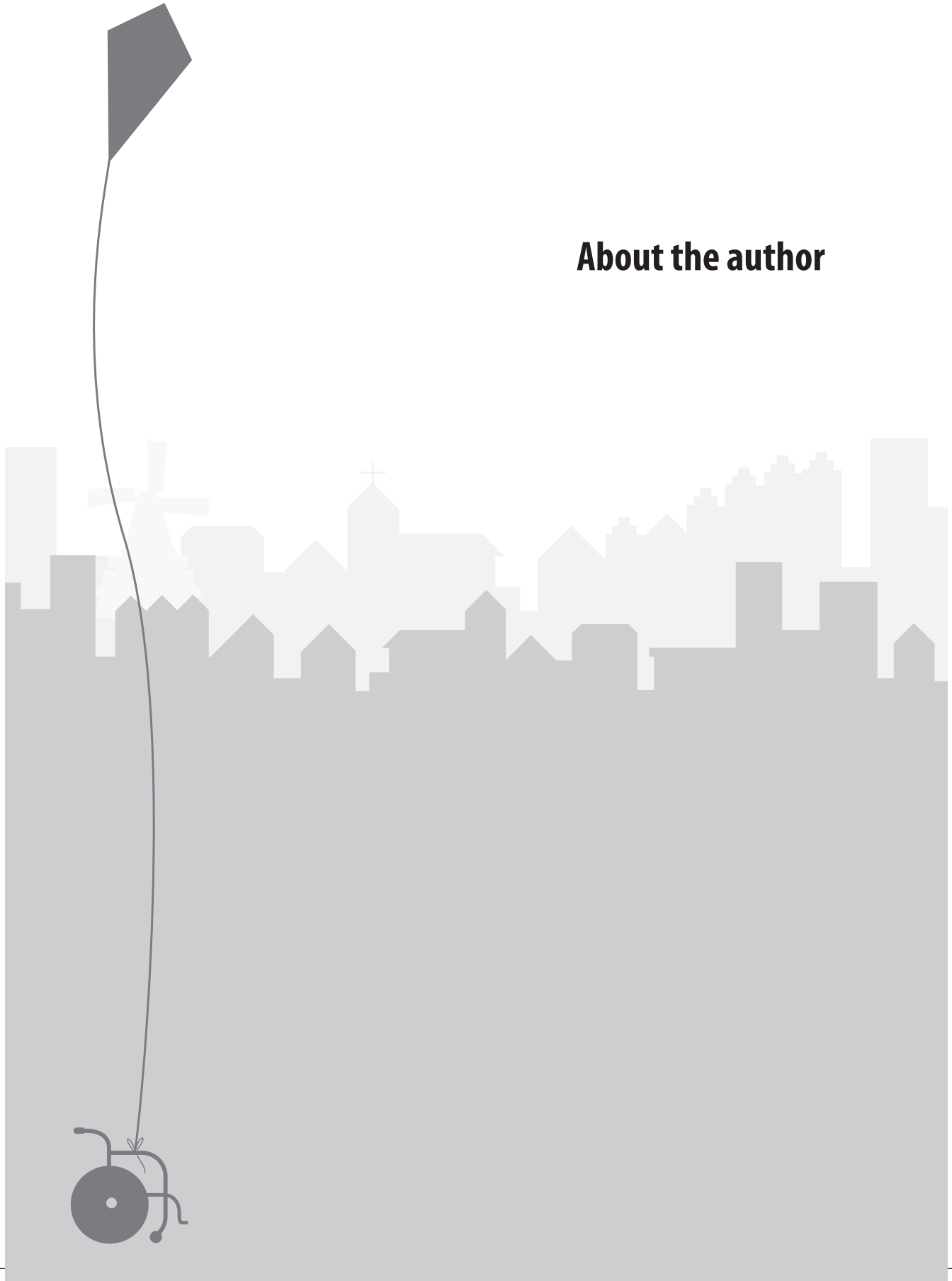
About the author



CURRICULUM VITAE

Maureen Bult werd op 19 april 1982 geboren in Enschede. In 2000 behaalde ze haar HAVO-diploma aan het Bonhoeffer College te Enschede (het toenmalige Jacobus College). Vervolgens heeft zij het eerste jaar van de opleiding verpleegkunde aan de Saxion Hogeschool in Enschede gevolgd en succesvol haar propedeuse afgerond. Van 2001 tot 2005 volgde zij de opleiding Pedagogische Wetenschappen aan de Radboud Universiteit in Nijmegen. Zij koos hier in het derde jaar voor de richting orthopedagogiek met als specialisatie lichamelijke handicaps. Na het behalen van haar Masterdiploma heeft zij een VSBfonds Beurs gekregen die zij heeft ingezet om in de periode 2006-2007 werkervaring op te doen als orthopedagoog en onderzoeker bij het Champion Center en de Canterbury Child Development Research Group (beide in Christchurch, Nieuw Zeeland). Na thuiskomst is zij van 2007-2009 als junior-onderzoeker verbonden geweest aan het Kenniscentrum van revalidatiecentrum de Hoogstraat in Utrecht. Zij was werkzaam op het project dat de validiteit en betrouwbaarheid van de Nederlandse versie van de Children's Assessment of Participation and Enjoyment (CAPE) onderzocht. Zij combineerde dit met haar werk als junior-orthopedagoog voor de afdeling jeugdrevalidatie in hetzelfde revalidatiecentrum. In het onderzoek werd Maureen enthousiast voor het onderwerp participatie. Na het kenbaar maken van haar wens om te promoveren en het verkrijgen van subsidie heeft zij zich vanaf 2010 als promovendus volledig ingezet voor het onderzoek. Maureen is sinds 1 mei 2012 werkzaam als post-doc bij het centrum Brein & Leren van de afdeling Onderwijsneurowetenschap aan de Vrije Universiteit in Amsterdam.

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Bult, M. K., Verschuren, O., Lindeman, E., Jongmans, M. J., & Ketelaar, M. Do children participate in the activities they prefer? Submitted.

Longo Araújo de Melo, O., Bult, M. K., Ketelaar, M., Badia Corbella, M., Orgaz Baz, B., & Jongmans, M. J. Participation in leisure activities of children and adolescents with and without cerebral palsy: comparing Spain and the Netherlands. Submitted.

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