Pediatric Evaluation of Disability Inventory (PEDI): calibrating the Dutch version

Jeltje Wassenberg-Severijnen

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Pediatric Evaluation of Disability Inventory (PEDI): Calibrating the Dutch version

Pediatric Evaluation of Disability Inventory (PEDI):
Standaardizering van de Nederlandse versie
(met een samenvatting in het Nederlands)

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Jeltje Eleonora Wassenberg-Severijnen

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Prof. Dr. A.Vermeer, Universiteit Utrecht
Prof. Dr. P.J.M. Helders, Universiteit Utrecht

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Contents

Chapter 1

Introduction

Introduction

Health is an important part of life of everyone. In our society, health is more than just the absence of diseases or disabilities. In the past, lots of efforts were taken to cure patients from their diseases and/or to reverse disabling conditions. If that was not possible, medicine would hardly pay attention to these patients. Although the consequences of having a disease or a disabling condition were recognized, they did not receive much attention. Nowadays, activity and participation are the most important goals in health care. The functioning of the individual in its own physical and social environment is the framework for studying and, if necessary, intervening the factors that influence health.

In 2001, the World Health Organization (WHO) presented the International Classification of Functioning, Disability and Health (ICF)[1] as a follow-up for the former International Classification of Impairments, Disabilities and Handicaps (ICIDH), edited in 1980[2]. In the ICF, all aspects of human functioning that can be related to health problems are systematically organized around three different perspectives:

1. Perspective of the human organism
2. Perspective of the human action
3. Perspective of man as participant in the community

The first perspective is found in the classification of physiological and mental functions of the organism and in the classification of anatomic properties. The second respectively third perspective have been worked out in the classifications of activities and participation. These classifications cover domains like ‘gather and apply knowledge’, ‘communication’, ‘mobility’, ‘self-care’, ‘household’ and ‘social interaction’. Additionally, external and personal factors are seen as factors that can influence human functioning and problems with human functioning. External factors result from the social and physical environment people live in, for example technical modifications, climate and population density. Personal factors refer to properties of the individual. Contrary to the ICIDH, human functioning is described in neutral terms which make it possible to view not only the negative health aspects but also the positive health aspects. Therefore, the ICF can be applied to all humans, not only to those having problems in their functioning. The ICF serve as a base for collecting data in health care and for developing different kinds of instruments in research, social policy and education.

Placing activity and participation in the centre of modern health has had serious impact on health care. Medicine made significant progressions in treating of life threatening diseases resulting in increased survival rates. Although curing diseases remains a very important aspect of contemporary medicine, not all

disabling conditions can be cured. However, these patients should be supported in other ways. As a result of these changes in the field of health and disease, medical rehabilitation received more and more attention. The goal of rehabilitation is to achieve optimal functioning within the constraints as set by the disabling conditions itself. Different disciplines like medicine, physical and occupational therapy and social sciences make their own contribution to the rehabilitation of the patient. When the patient is a child, there are several additional factors that should be taken into consideration.

Pediatric rehabilitation

In their early years children develop from creatures that totally depend on their parents to human beings who are independent in important facets of daily living by the time they face adolescence. Age is the most important factor in predicting the level of independence. Children pursue functional goals in their life, such as eating by themselves or playing games with other children and they possess various strategies to cope with their environments in order to reach their functional goals. Especially for young children, their family is the most important aspect of the environment in which they live. The presence of disabling conditions affect the child itself, but also its family, its peers and the educational setting. Children with disabilities also show development directed at independence, but in many cases their development is slower than that of children without disabilities or they never reach the stage of total independence. Therapy for these children used to focus on curing or changing the physical limitations of the child using intervention strategies that were developed for adults. Helders et al.[3] describe the changes in pediatric rehabilitation in the last decades. In the past, childhood development was considered merely a result of maturation, following predictable rules and a predictable sequence. Interventions were aimed to restore ‘normal’ behaviour and the (implicit) assumption was that the child could carry-over this behaviour to daily life. These interventions were in general designed for adults, and hardly adapted for use with children. However, research has failed to support this neuromaturational theory[3]: human behaviour turns out to be dynamic and adaptive[4], which means that the environment plays a very important role in the development of children. The Dynamic Systems Theory is an alternative foundation for research and intervention in pediatric rehabilitation[5], especially because variation in this theory is considered an important feature of development. Functioning, in this theory, is the result of a dynamic interaction of many subsystems in a specific context. Recently, the Neuronal Group Selection Theory is being used as a framework for normal and abnormal motor development. In this theory, genetics offer a general plan for the development, and by interacting with the environment using neuronal networks for feedback the most effective and broadly usable strategies for movement are selected[3].

As a result from these changes the focus of interventions in pediatric rehabilitation shifted from impairments to function, and from the child itself to its environment (family, peer, community). This approach facilitates reaching functional goals in children with disabilities[5,6].

Pediatric rehabilitation research

The changes in pediatric rehabilitation are related to the research that is done in this field. Research has lead to new theories about the mechanisms underlying human development. Despite these changes, many interventions in rehabilitation focused on impairments in stead of resolving functional problems. There is a 'scientification' of professions that used to just perform therapies. Interventions that have been used for decades now are undergoing serious questioning about effectiveness and efficacy[7], not only in diminishing the disabilities of the patient, but especially in ameliorating his or her functioning. The exhaustion of the financial resources in health care has probably accelerated this process. Insurance companies are no longer willing to pay for interventions of which effectiveness has not been proven.

In the Netherlands pediatric rehabilitation research has been initiated in order to evaluate existing and new kinds of therapy. At first, projects were mainly the result of local initiatives within one discipline, but more and more research is organized in cooperation networks like PERRIN (Pediatric Rehabilitation Research in the Netherlands) and NetChild. PERRIN, started in 1999, covers research on children with disabilities, especially children diagnosed with CP. NetChild, founded in 2003, is a multidisciplinary network (pediatric physical therapy, rehabilitation medicine and social sciences) for research about children with developmental disabilities. Important reasons for founding these networks are cooperation between disciplines that have the same goals, using knowledge of each other and connecting different investigations, continuity in research, and a complete presentation to organizations that support the research (financially). Within these networks pediatric rehabilitation research as a whole is more than the sum of its parts. Constructing instruments has special attention within these networks, because the results of studies largely depend on the reliability and validity of the instruments used.

The only way to prove the effect of a health care intervention is to measure its outcome. For this purpose, valid and reliable instruments are needed. Those instruments should focus on the functioning of the child in his or her environment because focus of rehabilitation is on this functioning, no longer on just impairments. Both age-specific capability and performance in the context of family and community should be addressed in the assessment of possible functional problems. The purpose of the assessment is to discriminate between normal and abnormal development given the age of the child, and to evaluate changes in functioning over time. When no such instruments exist in a certain country, it is possible to design a

new instrument, but this is very expensive and takes a lot of time. Another possibility is to use instruments that are designed to measure the phenomenon that is studied, but have been developed in another country. A review of existing outcome instruments[8] in pediatric physical therapy revealed only two instruments that proved to be useful both in the discrimination between children with and without disabilities and in the evaluation in changes over time, in the countries for which they were designed. These instruments were the Pediatric Evaluation of Disability Inventory (PEDI) and the Gross Motor Function Measure (GMFM). The GMFM is an observational instrument developed to measure gross motor function in children with cerebral palsy (CP) and was translated for use in the Netherlands[9]. The PEDI is also an interesting instrument which deserves being used in more countries than the United States of America. First, the PEDI follows the shift towards a functional focus that is also incorporated in Dutch pediatric rehabilitation. Furthermore, its psychometric properties are studied and found to be satisfactory[8, 10-14] and the important role of the environment is recognized and transformed into a part-to-measure. The translation, adaptation and calibration of a Dutch version of the PEDI are subject of this thesis.

PEDI

The Pediatric Evaluation of Disability Inventory is an instrument with which functional status can be measured in children aged between 6 months and 90 months (7.5 years). Functional status is the extent to which a child is independent of his parents in performing daily activities. The authors, Haley, Coster, Ludlow, Haltiwanger and Andrellos[10], stress the importance of using functional outcome measures because functional measures are consistent with treatment goals and functional measures emphasize independence, not normality.
The PEDI is based on an adaptation of the conceptual hierarchy of outcomes defined by the ICIDH, in 1990 the leading classification system of disability and health, provided by the World Health Organization (WHO))[2]. In the adapted model the concept of ‘functional limitations’ is added to bridge the gap between impairments and disability. Functional limitations refer to limitations that affect the *ability* to perform normal daily activities, whereas disability refers to problems in the *performance* of those daily activities. The model has been made suitable for use in pediatric rehabilitation by adding a developmental and a contextual framework[11]. In the actual International Classification of Functioning, Disability and Health (ICF)[1], these constructs are also incorporated, in the ‘activities’ component of this classification.

Performance depends on the capabilities of the child: when a child does not have sufficient skills no independent performance is possible and the child needs assistance of their parents. Furthermore, performance depends on the physical and

social environment the child lives in. This environment provides opportunities for the acquirement of the skills needed for an independent performance, but also has to give the child the chance of performing independently when he masters the necessary skills. The PEDI contains items to measure functional capability, and also items to measure the performance in three content domains: Self Care (SC), Mobility (M) and Social Function (SF) *Capability is measured by the assessment of the functional skills of which the child has shown mastery. These skills are rated in the Functional Skills Scales (FSS) and provide sufficient detail to identify clinical patterns of deficiencies in functional skill attainment. Actual performance is measured in the Caregiver Assistance Scales (CAS) by the extent of help a parent gives in daily functioning. Therefore, the CAS is an indirect measure of capability, whereas the FSS is a direct measure. The CAS provides additional information to the results of the FSS: when children have mastered certain skills, this does not mean that they use those skills in actual performance. The Modifications Scale (MS) is a frequency count of the type and extent of environmental modifications that support functional performance. Table 1.1 gives an overview of the content of the PEDI.

The PEDI was designed to use as an instrument

- to detect a functional deficit or delay, and if that exists, the extent and content area of the delay or deficit
- to evaluate individual or group progress in pediatric rehabilitation
- to evaluate programs in pediatric rehabilitation.

Administration of the PEDI can be done by professional judgment of a therapist or by structured interview and parent report. The PEDI can be used for children with various types of congenital and acquired disorders, and the authors[10] believe that the PEDI is most appropriate for measuring functional status in children with moderate or severe physical or combined physical and cognitive disabilities.

Measurement scales and summary scores

The items in the FSS are discrete and are accompanied by scoring criteria and sometimes examples of behaviour to help clarify scoring decisions. The items can be scored 0 or 1.

0 = unable or limited in capability to perform item in most situations

1 = capable of performing item in most situations, or item has been previously mastered and functional skills have progressed beyond this level

Table 1.1: Content of the PEDI

Domains	**Functional Skills Scale**		**Caregiver Assistance Scale Modifications Scale**
	Subscales	Number of items	
Self care	Types of food textures	4	Eating
	Use of utensils	5	
	Use of drinking containers	5	
	Tooth brushing	5	Grooming
	Hair brushing	4	
	Nose care	5	
	Hand washing	5	Bathing
	Washing body and face	5	
	Pullover/front-opening garments	5	Dressing upper body
	Fasteners	5	
	Pants	5	Dressing lower body
	Shoes/socks	5	
	Toileting task	5	Toileting
	Management of bladder	5	Bladder Management
	Management of bowel	5	Bowel Management
Mobility	Toilet transfers	5	Chair and toilet transfers
	Chair/Wheelchair transfers	5	
	Car transfers	5	Car transfers
	Bed mobility/transfers	4	Bed mobility/transfers
	Tub transfers	5	Tub transfers
	Indoor locomotion methods	3	Indoor Locomotion
	Indoor locomotion – distance/speed	5	
	Indoor locomotion – pulls/carries objects	5	
	Outdoor locomotion methods	2	Outdoor Locomotion
	Outdoor locomotion – distance/speed	5	
	Outdoor surfaces	5	
	Up stairs	5	Stairs
	Down stairs	5	
Social function	Comprehension of word meanings	5	Functional comprehension
	Comprehension of sentence complexity	5	
	Functional use of communication	5	Functional expression
	Complexity of expressive communication	5	
	Problem-resolution	5	Joint problem-solving
	Social interactive play (adults)	5	
	Peer interactions (child of similar age)	5	Peer play
	Play with objects	5	
	Self information	5	
	Time orientation	5	
	Self protection	5	Safety
	Community function	5	

The CAS assesses the amount of help the child receives to complete a complex functional activity using a six-point ordinal scale.

0 = total assistance: child totally depends on the caregiver
1 = maximal assistance: caregiver does more than half the effort needed for performance, but the child does provide some meaningful assistance
2 = moderate assistance: child does more than half the effort, but the caregiver provides substantial assistance
3 = minimal assistance: child does more than half the effort, the caregiver provides some assistance
4 = supervision: caregiver does not provide physical assistance, but supervises the performance
5 = independent: child performs the activity independent of the caregiver

The MS is not a measurement scale but a frequency count of types of modification required in performing the activity under ordinary circumstances:

N = no modifications
C = child oriented modifications, commonly used, non-specialized equipment
R = rehabilitation equipment, equipment normally not needed by non-disabled children
E = extensive modifications such as a wheelchair or major architectural alterations

The manual of the American PEDI[10] describes two kinds of summary scores: Normative Standard Scores and Scaled Scores. The Normative Standard Scores are transformed scores that depend on the age of the child: with these scores discrimination between children with and without disabilities is possible. For each age group, the scores have a mean of 50 and a standard deviation of 10, therefore a normative standard score can be directly interpreted in terms of deviation from the mean score in that age group. Scaled Scores give an indication of functional performance independent of age. The Scaled Scores vary from 0 to 100: 0 means that a child is not capable of performing even the easiest item, 100 means that the child has mastered all the items. Finally, with the aid of a computer program, goodness-of-fit tests can be computed in the original PEDI, to see whether the development of a child is consistent with the development of non-disabled children with the same raw score. There is an absence of fit when a child is capable of performing relatively difficult items but not capable of performing relatively easy items, a score pattern typically seen in children with particular disabilities.

Purpose of this research

When using the PEDI in a study on functional therapy in Dutch children with Cerebral Palsy (CP) researchers[6] encountered some problems with a literal translation of the PEDI. For example typical Dutch situations like use of a shower instead of a bath were difficult to score. Furthermore, in another research project using the original summary scores fit scores of Dutch children both with and without disabilities indicated absence of fit with the American order of acquiring functional skills, especially in the Social Function domain[15]. Investigation of item difficulties

confirmed these results: difficulties for American and Dutch children were not equal[16].The good properties of this instrument combined with the problems researchers experienced lead to the conclusion that before using the PEDI in the Netherlands, the PEDI should be translated, adapted, validated and standardized. This thesis describes the process and outcome of the adaptation of the PEDI.

Goal of this study was *to cross-cultural adapt, validate and standardize the PEDI for the Netherlands.*

This study was conducted by two researchers, a pediatric physical therapist (researcher 1, Custers) and a social scientist (researcher 2, Wassenberg-Severijnen), and consisted of three parts:
Part 1: translation and cross-cultural adaptation
Part 2: examining the content validity and reliability of the Dutch PEDI
Part 3a: examining validity of the Dutch PEDI in using it for children with disabilities
Part 3b: standardize the Dutch version
The researchers did part 1 and 2 together, whereas part 3a was done primarily by researcher 1, and part 3b primarily by researcher 2.

Outline of this thesis

In this thesis the adaptation of the Pediatric Evaluation of Disability Inventory for the Netherlands is described. First, in chapter 2, the adaptation process is described along with the results of the content validity study, which resulted in the PEDI-NL. In chapter 3 and 4, the psychometric properties of the PEDI-NL are studies: the reliability of the PEDI-NL is described in chapter 3, in chapter 4 it is shown that the PEDI-NL has discriminative power. Chapter 5 describes the standardization process, leading to Dutch normative standard scores needed for the use of the PEDI in the Netherlands. In chapter 6 a comparison is made between the American and the Dutch version of the PEDI, and in the final chapter the adaptation process is evaluated.

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Chapter 2

Dutch adaptation and content validity of the 'Pediatric Evaluation of Disability Inventory (PEDI)'

J.W.H. Custers[1], J.E. Wassenberg-Severijnen[2], J. van der Net[1],

A. Vermeer[2], H. 't Hart[3], P.J.M. Helders[1]

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[1]Department of Pediatric Physiotherapy, University Medical Center/Children's Hospital Utrecht, the Netherlands

[2]Institute for the Study of Education and Human Development, Utrecht University, the Netherlands

[3]Department of Methodology and Statistics, Faculty of Social Sciences, Utrecht University, the Netherlands

Abstract

Purpose: To adapt the American PEDI into a Dutch version, and to establish the content validity of this pediatric functional status instrument.

Methods: The adaptation process was based on current scientific guidelines in the field of cross-cultural research. Thirty-one allied health professionals completed a validity questionnaire for the content validity study.

Results: The topic ‘bicycling’ was added to the questionnaire, and adaptations of the text were made without losing the content of the original PEDI. At least 81% of the respondents rated that the most important facets in examining functional status in childhood were represented in the Dutch PEDI. Eighty-seven per cent and 71% of the respondents rated that the PEDI is feasible for discriminative purposes and evaluative purposes, respectively.

Conclusion: The expert panel confirmed the functional content and feasibility of the Dutch PEDI for pediatric rehabilitation outcome measurement.

Introduction

An era of assessment and accountability in medicine has provided health scientists with a wide variety of health-related outcome instruments[1]. Patrick & Deyo[2] warned that too many instruments for the same condition threaten the external validity of study findings. Moreover, the need for international collaboration that grew from limited (financial) resources in health research encouraged scientists to adapt already existing health outcome instruments to their needs, while maintaining good psychometric properties. Cross-cultural adaptation of existing outcome instruments evolved from a growing body of knowledge that recognized cultural differences between distinct concepts of health in different populations. It became apparent that literal translation of existing health outcome questionnaires lacked validity[2-9]. The first aim of this study was to adapt the 'Pediatric Evaluation of Disability Inventory' (PEDI)[10], a functional status instrument for infants and young children, for the Dutch population following current guidelines for cross-cultural adaptation[4,6]. Therefore, the criteria of the European Research Group on Health Outcomes (ERGHO), namely content equivalence, semantic equivalence, and conceptual equivalence were applied[6]. The second aim of this study was to perform a content validity study to confirm the functional content of the adapted Dutch PEDI. The adaptation process and the adaptations made, as well as the results of the content validity study, are reported in this paper. In future, additional reliability studies and validity studies have to complete the cross-cultural validation procedure. It will provide an outcome instrument feasible for use in a relatively small language domain, at costs far below the costs of developing a complete new outcome measure.

Cross-cultural adaptation

Cross-cultural research aims at the development of outcome instruments to measure the same phenomenon in different cultures, and to perform outcome studies of patient populations across cultures. Berry et al.[11] described three basic approaches in cross-cultural research. The first is the 'absolutist' approach, which assumes that concepts being measured will be largely invariant across cultures. Those who only translate an instrument rather than investigate the relevance of the concepts are following this approach. The second is the 'universalist' approach, which assumes that a context-free definition and measurement of concepts will be difficult or impossible to achieve, and that measurement in a cross-cultural context will require the need for adapted instruments. The third is the 'relativist' approach, which assumes that it is impossible to use standard instruments across cultures because the variation of the culture's behaviour is substantial. Adaptation of outcome measures mainly depends on the approach one favours.
The European Research Group on Health Outcomes (ERGHO) sets a minimum of criteria for cross-cultural adaptation[6]. These criteria are: content equivalence, together with semantic-, and conceptual equivalence. Content equivalence refers to

the observation whether the concept of each item is relevant to the cultural setting. Semantic equivalence is aimed at the emphasis that must be placed on retaining the essence of what is being asked or stated rather than obtaining a direct (literal) translation of the words. Finally, conceptual equivalence is when the instrument is found to be measuring the same concept in different cultures. This can be measured by comparing the outcome on specific study populations in the original and target culture.

Herdman et al.[7] reviewed definitions of equivalence in cross-cultural research, and found little similarity and clarity, especially in 'conceptual equivalence'. The interpretation of 'conceptual equivalence' varied, between authors, from similarity of the underlying theoretical concept to similarity of the meaning of the items and similar ranking of the items of a scale. Herdman therefore strongly suggested using standardized terminology in the cross-cultural adaptation of outcome instruments. 'Conceptual equivalence', in Herdman's opinion, does not exist at item level, but at a higher, more abstract level, that of the way a concept is organized and expressed in different cultures[7].

To meet the criteria of content and semantic equivalence, Guillemin et al.[4] stressed the importance of several forward and back translations performed by qualified, independent, and bilingual translators. These translators should preferably translate into their mother tongue. The differences identified should be addressed and when necessary the original developer should be contacted. Many researchers in this field[3,4,6] stated that a review committee should compare original and translated versions regarding content and construct of the questionnaire. Such a committee is also likely to modify or eliminate irrelevant, inadequate and ambiguous items and may generate substitutes better fitting the cultural target situation, while maintaining the general concept. After the instrument is modified by the review committee, pretesting has to be started. Analysis of the responses of the pretesting phase will identify problems in the interpretation of the content. It also reveals if questions give rise to reluctance or hesitation.

PEDI

The PEDI, developed by Haley et al.[10] is a clinical instrument for the assessment of functional status in children up to 7.5 years of age. It is a judgement-based parent-structured interview used by professionals in rehabilitation medicine. The PEDI is able to measure both capability (what the child can do) and performance (what the child actually does do) of routine daily childhood activities in the selfcare, mobility and social function domain, as is shown in table 2.1.

Table 2.1 Item content of the PEDI (US version): Subscales per domain.

Functional skills Scale		
Self-Care Domain	**Mobility Domain**	**Social Function Domain**
Types of food textures	Toilet transfers	Comprehension of word meanings
Use of utensils	Chair/wheelchair transfers	Comprehension of sentence complexity
Use of drinking containers	Car transfers	Functional use of communication
Tooth brushing	Bed mobility/transfers	Complexity of expressive communication
Hairbrushing	Tub transfers	Problem-resolution
Nose Care	Indoor locomotion- methods	Social interactive play
Hand washing	Distance/speed indoors	Peer interactions
Washing body and face	Pulls/carriers objects	Play with objects
Pullover/front-opening garments	Outdoor locomotion-methods	Self information
Fasteners	Distance/speed outdoors	Time orientation
Pants	Outdoor surfaces	Household chores
Shoes/socks	Upstairs	Self protection
Toileting tasks	Downstairs	Community function
Management of bladder		
Management of bowel		

Capability of a child can be measured using the three functional skills scales of the PEDI. These scales contain a total of 197 questions, which are supported by an explanatory part. Performance of a child can be measured using the three caregiver assistance scales and modification scales of the PEDI. [10] The caregiver assistance scales contain 20 questions concerning the same activities of the functional skills scales. The modification scales are measures of environmental modifications and equipment used by the child in routine daily activities. The construct of the PEDI is presented in table 2.2.

Table 2.2 Construct of the PEDI (US version): Domains, scales and number of items in the PEDI.

	PEDI scales		
	Capability	*Performance*	
PEDI Domains	Functional skills scale	Caregiver assistance scale	Modifications scale
Self care	73	8	8
Mobility	59	7	7
Social Function	65	5	5
Format	Dichotomous	6-point ordinal scale	4-point ordinal scale

Although the PEDI is primarily designed for functional evaluation of young children, the PEDI can also be used for the evaluation of older children if their functional abilities fall below that of children up through the age of 7.5 years. The PEDI is an appropriate instrument for measuring functional status in children with physical or both physical and cognitive abilities. It is a less suitable instrument for assessing infants less that one year of age and for assessing older children with minimal disability. Its validity for children whose primary disability is behavioural or social, whose functional performance shows significant fluctuations, or whose functional limitations are thought to be in the mild to moderate range is still under investigation[10]. The PEDI is intended to be used to discriminate between non-disabled and disabled children, and to guide and evaluate pediatric rehabilitation programmes. Extended reliability and validity studies with the original PEDI were published[10,12-16]. Haley et al.[17] performed a content validity study in the developing phase of the PEDI. This study provided information whether the items of the PEDI, both individually and as a whole, represent the construct that is was supposed to measure. The respondents who participated in that study confirmed the accuracy of the content of the PEDI.

Dutch adaptation process of the PEDI

In line with ERGHO, the 'universalist' approach was adopted, which assumes that measurement in a cross-cultural context requires the use of adapted instruments[11]. The main argument was based on the findings of a preliminary study of Custers et al.[18] in which the responses on the PEDI of 20 healthy Dutch children were investigated and compared with American peers. In this study, person fit was analysed according to the Rasch model[19,20]. Score profiles of the Dutch children were found to be incompatible with the score profiles of American peers, indicating cultural differences. It was agreed upon that a cross-cultural adaptation procedure of the PEDI was inevitable.

To obtain content, semantic, and conceptual equivalence,[6] the Dutch adaptation process of the PEDI was based on the guidelines for cross-cultural adaptation of Herdman et al.[7], Bullinger et al. [3], Guillemin et al.[4] and Touw-Otten and Meadows[6], meeting the criteria of the ERGHO.

In accordance with Herdman et al.[7], the interest was in whether the underlying concept of the PEDI was appropriate to use in the Netherlands. The theoretical concept of the PEDI is based on the disablement model of Nagi[21]. Two concepts of this model, 'functional limitations' and 'disability', are implemented in the PEDI[10,22]. Current modifications of this model were made by Jette and Verbruggen[23], and the US National Centre for Medical Rehabilitation Research (NCMRR)[24]. At the moment, it is still a leading model in health related outcome studies in the USA. Recently, this model was also used in Swedish and Dutch health related outcome studies[25-27]. Moreover, the latest draft of the WHO's 'International Classification of Impairments, Disabilities, and Handicaps' (ICIDH2-B2)[28], although still undergoing evaluation,

shows more and more similarity with the modified disablement model of Nagi[21]. Since the underlying concept of disability, i.e. limitations of daily activities, does not differ significantly, it is felt that the underlying concept of the American PEDI is appropriate to use in the Netherlands. Therefore, the 'relativist' approach[11], which assumes that the PEDI is not feasible to use at all was rejected.

A certified translator translated the PEDI into the Dutch language. She was previously informed about the PEDI, the aim of the translation, and the criteria stated by Guillemin et al.[4]. The Dutch translated version was then subjected to an adaptation process. A multidisciplinary review committee compared the original and translated version. The members of this committee were professionals in the pediatric rehabilitation field (n= 4) or researchers in educational sciences (n= 2). This committee investigated 'content equivalence' and 'semantic equivalence' by reviewing and adapting the PEDI items attentively. They also investigated additionally the accuracy of the items in terms of ambiguity and completeness, and the construct of the items in terms of redundancy of text. Although, it was intended to change the PEDI only if necessary, the following adaptations were made:

- Dutch related behaviours were implemented in the following subscales:
    1. The item 'makes successful attempts to eat with a knife *and* fork simultaneously' was added (subscale 'use of utensils'- 'functional skills scale').
    2. In the items concerning tub transfers, 'shower' was added (subscale 'tub transfers'- 'functional skills scale' and 'caregiver assistance scale').
- Weights and measures were converted to the metric system. For example, the distance in feet (subscale 'outdoor locomotion') has been changed into metres; and the size of a half-gallon of milk (subscale 'use of drinking containers') was changed into 1 litre of milk.
- Literal translated words were changed into Dutch- idiom. For example the subscale 'bowel management', which was at first translated as 'stoelbeheer', was changed into the less formal word 'poepen'.
- Three new items were added to the following subscales of the 'Functional Skills Scale':
    1. 'Can change position in a bed equipped with a railing' (subscale 'bed mobility/transfers').
    2. 'Walks without support and is able to carry something in the hands at the same time' (subscale 'outdoor locomotion-methods').
    3. 'Devices plans for and plays a game together with another; the playing lasts longer than 30 minutes and is complex' (subscale 'peer interactions').
- Items were more consequently divided into a 'question' and a supportive 'explanatory' part as is shown in table 2.3.

Table 2.3 Modification of an item.

	Functional Skills Scale: Problem-Resolution item 23	
	Question	*Explanation*
PEDI USA version	'When a problem occurs, child can seek help and wait if it is delayed a short time (The child cries "can't do it!" but calms when told "I can help you in just a minute")'	'The child knowledge that help will be available soon is sufficient to help him/her sustain control when distressed, for short periods of time. However, the child still shows limited tolerance for delays of more than a few minutes.'
Dutch PEDI	'If something doesn't work or a problem occurs, the child seeks help and can wait a little while before help is offered.'	'For the child, the knowledge that help is coming quickly is enough to be able to manage him/herself for a short time when he/she is upset. However, the child still shows impatience during the few minutes of waiting. For example: The child cries out, "I can't do it!" but calms down when told, "I'm coming to help you."'

A specified list of adaptations and motives for these adaptations is presented in the appendix. No items were eliminated from the original PEDI. A bilinguist and American native speaker with experience in translating documents for the biomedical industry then back-translated the Dutch version of the PEDI. She was also previously informed, comparable to the first translator, about the aim of the translation, the criteria and the PEDI's construct. The Dutch translated version, as well as the back-translated version, a letter of recommendation and a list of adaptations were sent to the authors of the PEDI. They authorized this first draft of the Dutch PEDI.

Content validity

Haley et al.[17] stated that content validity could be considered as an index of whether the items of the PEDI, both individually and as a whole, represent the construct that is supposed to measure. Although a content validity study originally had been performed by Haley et al.[17], because of the adaptations made, the content validity and clinical feasibility of the Dutch translated PEDI had to be re-established.

Methods

Participants

Previously, different allied health professionals familiar with functional status of infants and young children were selected. Thirty-two professionals were solicited to participate, of which 31 (male: female = 4: 27) returned the completed validity questionnaire. None of them was involved in the Dutch adaptation process of the PEDI. One respondent replied anonymously. Professionals represented were pediatric physical therapists (n=15), special educators (n=4), occupational therapists (n=3), physicians at infants healthcare centre (n=3), pediatric rehabilitation doctors (n=3), scientific co-workers (n=2), and one speech and language therapist. Eleven

respondents were working in a pediatric rehabilitation centre, whilst the other respondents were working in a (university-) children's hospital (n=8), a clinic for pediatric physical therapy (n=6), an infants healthcare centre (n=3), and at the university (n=3). Mean age of the respondents was 44 years (SD = 9). The professionals average years of experience in child health services was 19 years (SD = 8.82). Fourteen of the respondents had an academic degree in their respective fields (PhD, MA, Msc, MD). Seven of the respondents were familiar with the PEDI.

Validity questionnaire

The validity questionnaire consisted of three sections. In the first section the respondents were asked for their age, highest level of education, working experience, and the degree of familiarity with the PEDI. The second section consisted of 18 questions. Of those, seven questions could be rated on a nominal scale ('yes/no', 'good/not good'). These questions asked for the accuracy of the content, and the clinical feasibility of the Dutch PEDI.
The other 11 questions could be rated on a five-point ordinal scale and asked for the discriminative- and evaluative power per domain (ranging from 'very bad' to 'very good'), and the length of the PEDI (ranging from 'too short' to 'too long'). The third section consisted of 12 questions where respondents could rate the accuracy per item and whether any items should be added or deleted ('yes/no'). Specific feedback information could be written about any of the items.

Analysis

Data are presented for each question by percentages of each response. Written feedback will be presented in the results section (qualitative part).

Results

Quantitative

The 18 and 12 questions respectively, of the second and third section of the validity questionnaire, consisted of similar questions for the Selfcare domain, Mobility domain, and Social Function domain. For this paper, these questions were clustered into eight topics, which are presented in tables 2.4 - 2.11.

Table 2.4 Are the most important facets represented in the particular domains?

	Selfcare	Mobility	Social function
Yes	97%	84%	81%
No	3%	16%	19%

% of respondents that rated this answer.

Table 2.5 Rate the potential of the PEDI to discriminate between non-disabled and disabled children.

	Selfcare	Mobility	Social function	Overall
Very bad	-	-	3%	-
Bad	3%	3%	7%	-
Neutral	10%	7%	29%	13%
Good	68%	84%	58%	84%
Very good	13%	7%	3%	3%
Missing value	*7%*	-	-	-

% of respondents that rated this answer.

For example, 97 % of the respondents found that the most important aspects of the Selfcare domain were represented, as to 84% and 81% of the mobility domain and social function domain, respectively (table 2.4). Eighty seven per cent replied that the potential of the overall PEDI to discriminate in functional status was 'good' (84%) or 'very good' (3%) (table 2.5). With respect to the evaluative potential of the overall PEDI, a lesser degree of satisfaction (59%) is marked (table 2.6).

Table 2.6 Rate the potential of the PEDI to identify meaningful change in functional status.

	Selfcare	Mobility	Social function	Overall
Very bad	-	-	3%	-
Bad	16%	13%	26%	10%
Neutral	16%	16%	16%	23%
Good	61%	61%	45%	52%
Very good	7%	7%	3%	7%
Missing value	-	*3%*	*7%*	*10%*

% of respondents that rated this answer.

Table 2.7 Rate the feasibility of the PEDI regarding discriminative and evaluative purposes.

	Discriminative purposes	Evaluative purposes
Not good	3%	10%
Only after modifications	10%	3%
Good	87%	71%
Missing value	-	*16%*

% of respondents that rated this answer.

Table 2.8 Rate the feasibility to administer the PEDI to parents and professionals.

	Parents/ caregivers	Therapist/ rehabilitation team
Very bad	-	-
Bad	-	16%
Neutral	10%	26%
Good	74%	52%
Very good	13%	7%
Missing value	*3%*	-

% of respondents that rated this answer.

For both the discriminative- and evaluative potentials, the respondents rated the satisfaction of the social function domain slightly lower than the selfcare and mobility domain. The feasibility of the PEDI with respect to discriminative- and evaluative purposes was almost rated similarly with the topics before (table 2.7). Eighty-seven per cent rated the feasibility to administer the PEDI on parents/caregivers to be 'good' (74%) or 'very good' (13%) (table 2.8). This is in contrast with the degree of satisfaction with respect to the feasibility to administer the PEDI on therapists and rehabilitation teams (59%) (table 2.8).

Table 2.9 Rate the length of the PEDI.

Too short	-
Short	-
Average	13%
Long	71%
Too long	16%

% of respondents that rated this answer.

Table 2.10 Would you add items to the PEDI?

	Selfcare	Mobility	Social function
Yes	32%	42%	23%
No	58%	55%	61%
Missing value	*10%*	*3%*	*16%*

% of respondents that rated this answer.

Table 2.11 Would you remove items from the PEDI?

	Selfcare	Mobility	Social function
Yes	7%	16%	10%
No	87%	74%	71%
Missing value	*7%*	*10%*	*19%*

% of respondents that rated this answer.

A majority of the respondents is of the opinion that the PEDI is 'long', while 16% rated the PEDI as 'too long' (table 2.9). Lastly, a majority of the respondents would not add items to the particular domains (table 2.10), and slightly more respondents would not remove items from the particular domains (table 2.11).

Qualitative

The majority of the respondents gave specific feedback information, which is presented in this section. With regard to the question whether all the important facets are represented (table 2.4), the most important item that was found to be absent in the Mobility domain was riding a bicycle. This was reported by 10 respondents. Other items, less frequently reported, concerned cognitive skills, interactions with the child's siblings, and school functioning. With regard to the discriminative and evaluative properties of the PEDI (tables 2.5 and 2.6), the respondents reported that the discriminative-, and evaluative power might decrease when measuring children with minor functional limitations (such as 'Attention Deficit and Hyperactivity Disorder'), children with a variable degree of disease-severity (as can be found in children with 'Juvenile Idiopathic Arthritis'), children with severe mental retardation, children with autistiform behaviour (such as 'Pervasive Developmental Disorder- Not Otherwise Specified'), children with sensorial impairments, and very young children as well as children above the target age-group (i.e. between 6 months and 7.5 years). Written comments of some respondents suggested that there are too large steps between the subsequent items to measure clinically meaningful change in functional status. With regard to the feasibility to administer the PEDI to parents and professionals (table 2.8), respondents reported that the PEDI is probably too detailed to administer it to therapists, in particular because of the lack of information regarding the amount of assistance in home-based activities. General comments were reported concerning the presence of spelling-mistakes and inconsistent usage of language. One respondent missed qualitative aspects of performance, such as starting position and quality of movement.

Discussion

Dutch adaptation of the PEDI

The aim of the adaptation process was to develop a Dutch PEDI, which is the equivalent of the original USA version. Leading guidelines were followed[3,4,6,7] for cross-cultural adaptation. The majority of the adaptations made by the review committee were based on methodological motives, like the restructuring of the content of the manual in a 'question' and a supportive 'explanatory' part. New items were added because all the members of the review committee agreed that these items would strengthen the construct of the scales. A small number of adaptations were made because of cultural motives, such as the addition of 'the usage of utensils simultaneously' in the subscale 'use of utensils', which is suggested to be a culture specific behaviour. The fact that a relatively small number of adaptations were made because of cultural motives supported the assumption that the underlying concept of the American PEDI is appropriate to use in the Netherlands.

Content validity

While adaptations were made in the content of the PEDI, it was decided to re-establish the content validity. It also enabled a comparison of our results with the US content validity study, performed in the developing phase of the PEDI by Haley et al.[17]. The data of the validity questionnaire indicate that there is at least 81% satisfaction about the overall content of the Dutch PEDI. This is in agreement with the study findings of Haley et al.[17], who reported that 80% of the respondents in the USA were satisfied. Although, the majority of the respondents would not add items in the particular domains, they suggested 'riding a bicycle' frequently as a topic that could improve the mobility domain. Bicycling can be considered as an important functional skill in the Netherlands. Brouwers-de Jong et al.[29] reported that a majority of the Dutch children learn to tricycle at preschool age. Bicycling is the main means of transportation to go to school, friends or shopping centres in the Netherlands. Therefore, the item bicycling was added to the mobility domain of the functional skills scale. Based on the content validity study, no further items were added to the questionnaire.

A majority of the respondents were of the opinion that the Dutch PEDI has good potentials to discriminate between disabled and non-disabled children. A lower percentage of the respondents, but still a majority, have the same opinion regarding the evaluative potentials, i.e. to measure clinically meaningful change in functional status. In both cases, the social function domain was markedly lower rated than the selfcare and mobility domain. This is in agreement with the study findings of Haley et al.[17] 'Respondents in the US found the PEDI to be a more appropriate index of functional status than a measure of functional change', and 'More concern was expressed about the use of the PEDI as an evaluative instrument in the area of social function (46.4% good or excellent)'[17]. The intention of the authors of the PEDI to include social skills was 'to measure behaviours that had functional relevance, in contrast to developmental tests that are more concerned with achievement of specific components that underlie functional performance'[17]. It is supposed that changes in this more abstracted level of social skills, rendered as behaviour, are more difficult to measure over time. Overall, the Dutch PEDI was judged to be a clinically feasible instrument, both for discriminative and evaluative purposes.

The suggestion of the respondents that the discriminative- and evaluative potentials are less powerful in specific patient groups, like children with 'Attention Deficit and Hyperactivity Disorder', is in agreement with and supports the directives of the PEDI's manual[10]. It is noteworthy that the PEDI is to be found 'long' or 'too long' by a majority of the respondents. Despite this, the same number of respondents was not prepared to remove any of the items of the particular domains. Some respondents even suggested that there are too large steps between the subsequent items to measure clinically meaningful change in functional status. This paradox was also present in the study of Haley et al[17]. More (smaller) steps between item levels led to a larger number of items resulting in lengthening the instrument

and thus the assessment. This does not serve the practicability. The length of the PEDI might be reduced by selecting a target scale; each PEDI scale is self-containing and can be used separately[10]. Developing instruments is an on-going process. In the future, it will be necessary to investigate the possibility whether short forms of the PEDI can be developed for different age classes. This could serve the practicability without loosing the instrument's evaluative power. The opinion of the respondents that the PEDI is more appropriate to be administered to parents as compared to therapists is supported. In our experience using the PEDI, therapists are too less familiar with specific selfcare activities, social function skills, and amount of caregiver assistance at home. One respondent missed the point of 'quality of movement' in the judgement whether a child does or does not master the skill. The emphasis of the PEDI, however, is to measure the quantitative level of functional status. The suggestions of the respondents regarding spelling-mistakes and inconsistent usage of language were gratefully applied in the revised version. Overall, the expert panel confirmed the functional content of the Dutch PEDI and their comments improved the quality of the content. The corresponding data of the content validity study compared with the results in the USA supported the conceptual equivalence of the Dutch PEDI.

In conclusion, it is stated that the conceptual-, semantic-, and content equivalence of the Dutch PEDI, as compared with the American version, is established by this cross-cultural adaptation and content validity study. More validity studies (known-group validity, construct validity, responsiveness to change) will be performed to confirm the conceptual equivalence of the Dutch PEDI. As equivalence is also necessary with regard to reliability, additional studies (inter-respondent, inter-interviewer, and test-re-test reliability, as well as internal consistency) were started.

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Appendix I

Items added to the Functional Skills scale of the PEDI, based on the adaptation process.

Question: Makes successful attempts to eat with a knife and fork simultaneously.
Explanation: Cuts with a knife and fork and brings the food to the mouth.
(Item 9a, subscale 'Use of utensils', Selfcare domain)

Question: Can change position in a bed equipped with a railing.
Explanation: The child can change the position of his/her head, trunk and limbs.
(Item 16a, subscale 'Bed transfers', Mobility domain)

Question: Walks without support and can carry something in the hands at the same time.
Explanation: The child walks outside on most sorts of surfaces without needing support from a walking aid or the caregiver and carry a book bag, for example.
(Item 39a, subscale 'Means of locomotion, outside the house', Mobility domain)

Question: Devises plans for and plays a game together; the playing lasts longer (30-60 minutes) and is complex.
Explanation: The child begins of his own accord a shared activity (such as playing hide and seek or marbles) with one or more other children and continues doing exclusively that for a specific time. While playing, the child is able to negotiate with and attune his play to the other child. For example: it is decided who gets to take turn first, who gets assigned a certain role, etcetera.
(Item 34a, subscale 'Interactions with other children of the same age', Social Function domain)

Appendix II

Subscale and items added to the Functional Skills scale of the PEDI, based on the content validity study.

Subscale 'Bicycling', Mobility domain
Introduction: These items are related to the child's ability to transport him/herself by means of a bicycle. Leave the aspect of traffic safety conditions out of the evaluation.

Question: Can ride a (specially adapted) three-wheeler.
Explanation: The child is able, without help, to get on and off a (specially adapted) three-wheeler and moved forward by turning the pedals.

Question: Can ride a bicycle with training-wheels for at least 10m.
Explanation: The child is able, without help, to get on and off a bicycle and to ride it independently.

Question: Can ride a bicycle for at least 50m. .
Explanation: The child is able, without help, to ride 50m. on a bicycle with no training-wheels. Help with getting on and off the bicycle and verbal instructions are permitted.

Question: Can ride a bicycle without help for at least 100m. .
Explanation: The child is able, without help, to get on and off a bicycle with no training-wheels and to ride it independently.

Chapter 3

Reliability of the Dutch 'Pediatric Evaluation of Disability Inventory' (PEDI)

J.E. Wassenberg-Severijnen[1], J.W.H. Custers[2], J.J. Hox[3],

A. Vermeer[1], P.J.M. Helders[2]

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[1]Institute for the Study of Education and Human Development, Utrecht University, the Netherlands

[2]Department of Pediatric Physiotherapy, University Medical Center/Children's Hospital Utrecht, the Netherlands

[3]Department of Methodology and Statistics, Faculty of Social Sciences, Utrecht University, the Netherlands

Abstract

Objective: To evaluate the reliability of the Dutch version of the 'Pediatric Evaluation of Disability Inventory' (PEDI), an instrument for measuring functional status (capability and performance in self-care, mobility and social function) of young children using parent interviews.
Design: Inter-interviewer reliability was studied after scoring audiotaped interviews by a second researcher. For test-retest reliability the same parent was interviewed twice within three weeks; in inter-respondent reliability both parents of a child were interviewed independently within a few days. On item level, percentage identical scores were computed, and on scale level intra-class correlation coefficients (ICC) and Cronbach's alphas were calculated.
Subjects: Parents of 63 non-disabled and 53 disabled (various diagnoses) children aged between 7 and 88 months were interviewed.
Results: On scale level, all ICC's were above .90 and Cronbach's alpha was .89 for the self-care domain, .74 for the mobility domain and .87 for the social function domain. On item level for the Functional Skills Scale, the mean percentage identical scores varied from 89 to 99, and for the Caregiver Assistance Scale from 54 to 90. Different scores between interviewers resulted partially from ambiguous interpretation of the item and/or the explanation.
Conclusions: Although small adaptations have to be made, the reliability of the Dutch PEDI is found to be good.

Key words: PEDI, reliability, cross-cultural adaptation

Introduction

The 'Pediatric Evaluation of Disability Inventory' (PEDI) was developed to measure functional status in young children[1-3]. The PEDI can be used both for discriminative and evaluative purposes, and meets criteria of reliability and validity[1,3-6]. This instrument, originally developed for the North-American population, has recently been translated and cross-culturally adapted for use in the Netherlands[7]. In the adaptation process four new items were added, while many other items were adapted. Therefore, this series of investigations was designed to establish the psychometric properties of the Dutch PEDI. First, inter-interviewer reliability was studied to find out whether items and the accompanying explanation are interpreted in a uniform way. Second, internal consistency was established by studying the extent in which items within a scale are related. Third, test-retest reliability was examined to give an indication of stability of measures and last, inter-respondent reliability was studied to find out if there are differences in the judgements of both parents.

PEDI

The 'Pediatric Evaluation of Disability Inventory' measures functional status in children aged between six months and seven and a half years. Both the capability of the child and the amount of help they get from their parents as well as the equipment used in daily tasks are measured by a structured interview with parent(s). Functional status is determined in three domains: self-care, mobility and social function. Table 3.1 gives an overview of topics in the PEDI.

Items in the Functional Skills Scale (FSS, 201 items), measuring capability, are dichotomous and are scored either 'capable' or 'not capable'. Summed scores can be computed in every domain; the American version also gives standardized scores. The Caregiver Assistance Scale (CAS, 20 items), measuring the amount of help, is an ordinal six point-scale, ranging from 'totally dependent' to 'totally independent'. The Modification Scale (MS, 20 items), measuring the equipment used, is also an ordinal scale.

An example of an item from the Functional Skills Scale is selfcare, item 53*:*

Item 'The child takes off pants, including opening of fasteners'

Explanation **'**The child must be capable of opening snaps, buttons and zippers. Belt buckles are not included'

Table 3.1 Content of the Dutch PEDI.

	Functional Skills Scale		Caregiver Assistance Scale and Modifications Scale
Domains	Subscales	Number of items	
Self care	Types of food textures	4	Eating
	Use of utensils	5 + 1[a]	
	Use of drinking containers	5	
	Tooth brushing	5	Grooming
	Hair brushing	4	
	Nose care	5	
	Hand washing	5	Bathing
	Washing body and face	5	
	Pullover/front-opening garments	5	Dressing upper body
	Fasteners	5	
	Pants	5	Dressing lower body
	Shoes/socks	5	
	Toileting task	5	Toileting
	Management of bladder	5	Bladder Management
	Management of bowel	5	Bowel Management
Mobility	Toilet transfers	5	Chair/toilet transfers
	Chair/Wheelchair transfers	5	
	Car transfers	5	Car transfers
	Bed mobility/transfers	4 + 1[a]	Bed mobility/transfers
	Tub transfers	5	Tub transfers
	Indoor locomotion methods	3	Indoor locomotion
	Indoor locomotion – distance/speed	5	
	Indoor locomotion – pulls/carries objects	5	
	Outdoor locomotion methods	2 + 1[a]	Outdoor Locomotion
	Outdoor locomotion – distance/speed	5	
	Outdoor surfaces	5	
	Up stairs	5	Stairs
	Down stairs	5	
Social function	Comprehension of word meanings	5	Functional comprehension
	Comprehension of sentence complexity	5	
	Functional use of communication	5	Functional expression
	Complexity of expressive communication	5	
	Problem – resolution	5	Joint problem-solving
	Social interactive play (adults)	5	
	Peer interactions (child of similar age)	5 + 1[a]	Peer play
	Play with objects	5	
	Self information	5	
	Time orientation	5	
	Play with objects	5	
	Self protection	5	Safety
	Community function	5	

[a]Items added in the Dutch version

Methods

Participants

In testing the Dutch PEDI we interviewed parents of children with disabilities (*n* = 53) and without known disabilities (*n* = 63). The children without known disabilities were between two and three years old (mean 31 months, SD 3.6). A first group consisted of children visiting a primary health care centre for infants where growth and development of healthy children is recorded routinely. The health care centre sent a letter with an outline of the study and a request to participate to parents of all children aged two and living in a small town in the centre of the Netherlands (*n*= 260). Parents of 43 children were interviewed (a response of 17%). A second group of non-disabled children were already participating in another study when they were asked to participate in this study: 20 of them agreed.

The children with disabilities in this study were between 7 and 88 months of age (mean 42 months, SD 21.6) and are known to the children's hospital. They have neurometabolic disorders (*n* = 29), spina bifida (*n* = 7), osteogenesis imperfecta (*n* = 11) and infantile encephalopathy (*n* = 6). All children have stable or slowly progressive limitations in performing daily activities. After visiting the outpatient's clinic parents were asked to participate in this study.

Parents who agreed to participate were asked whether they also agreed into audiotaping the interview, whether it was possible to interview also the other parent, and/or to (partially) redo the interview within a few weeks. In sum, we audiotaped 31 interviews, we interviewed both parents of 32 children, while 20 parents were interviewed twice within a few weeks.

Analysis

Inter-respondent- and inter- interviewer reliability was established using scores from both disabled and non-disabled children. In all reliability studies we first looked at the proportion of identical answers in every item. Although Cohen's kappa is the usual measure of correspondence, its size depends on variance in answers. However, dichotomous skill-questions didn't always vary that much because of the rather homogenous group of non-disabled children. Therefore, we decided to use the proportion of identical answers in every item instead of Cohen's kappa. In addition intra-class correlation coefficients (ICC) were calculated.

In studying test-retest reliability the same parent of the same child was (partially) interviewed twice: mean time between the two interviews was 14.9 days (SD 3.6 days). The mean time between interviews of both parents was 3.9 days (SD 4.8 days) and parents were requested not to discuss the interview before they were interviewed both.

Results

Because of the different type of scales, the results are presented in different tables. Summed scores of the FSS are presented in Table 3.2 and scale results in Table 3.3. The scale results of the CAS and the MS are presented in Table 3.4.

Table 3.2 Summed scores of the Functional Skills Scale: mean (standard deviation).

		Self-care (74 items)	Mobility (61 items)	Social function (66 items)
Inter-interviewer	Researcher 1	35.4 (21.0)	36.6(20.1)	32.2 (20.3)
	Researcher 2	35.0 (20.8)	36.4 (20.3)	31.9 (20.2)
		t = 1.20 (*p* = .241)	*t* = 1.10 (*p* = .283)	$t = 1.17$ (p = .277)
Test-retest	First interview	27.3 (16.7)	33.8 (16.6)	33.4 (16.2)
	Second interview	26.3 (16.7)	33.1 (17.1)	35.6 (13.8)
		t = .80 (*p* = .455)	*t* = .73 (*p* = .486)	$t = -1.83$ (p = .100)
Inter-respondent	Mother	33.3 (19.1)	36.3 (19.7)	32.6 (16.9)
	Father	32.1 (19.2)	35.1 (18.7)	30.9 (17.3)
		t = 1.78 (*p* = .086)	*t* = 1.51 (*p* = .142)	$t = 1.79$ (p = .084)

Table 3.3 Results of the Functional Skills Scale: mean (standard deviation).

		Self-care (74 items)	Mobility (61 items)	Social function (66 items)
Inter-interviewer	% identical score	97.7 (3.1)	98.8 (2.5)	96.7 (3.6)
	ICC	.99	.99	.99
Test-retest	% identical scores	92.1 (11.6)	95.0 (6.8)	91.5 (10.3)
	ICC	.98	.98	.98
Inter-respondent	% identical scores	89.9 (6.9)	91.4 (6.5)	89.2 (7.0)
	ICC	.99	.99	.97

Table 3.4: Results of the Caregiver Assistance Scale (CS) and the Modifications Scale (MS): mean (standard deviation).

		Self-care (8 items)	Mobility (7 items)	Social function (5 items)
Inter-interviewer	% identical scores	CS 85.6 (8.3)	CS 90.1 (6.0)	CS 80.6 (9.4)
		MS 84.1 (8.4)	MS 87.7 (5.6)	MS 99.2 (1.8)
	ICC	CS .99	CS .99	CS .99
Test-retest	% identical scores	CS 81.3 (18.7)	CS 71.9 (11.9)	CS 54.0 (11.4)
		MS 92.7 (9.1)	MS 91.1 (11.9)	MS 94.0 (13.4)
	ICC	CS .97	CS .94	CS .91
Inter-respondent	% identical scores	CS 66.8 (11.9)	CS 66.9 (13.5)	CS 61.4 (6.6)
		MS 87.6 (7.0)	MS 82.9 (13.2)	MS 95.0 (11.2)
	ICC	CS .91	CS .97	CS .93

In inter-interviewer reliability it was possible to study the differences found because the interviews were audio taped. For the FSS, differences resulted from ambiguous interpretation of item and/or explanation in one third of the differences, especially in items where correspondence was relatively low. For example, item 41 in the social function domains is 'Can say its own name'. From the explanation it was not clear whether a child is capable only if they pronounce their name correctly, or also when they call themselves consequently in the same manner but not correct (which is often the case when a child has a name that is hard to pronounce). In the other two third of the differences, one of the researchers scored inaccurate. Sometimes it was very obvious, in other cases parents gave an explanation after their judgement 'capable' or 'not capable' by which the initial answer turned out to be incorrect. Both the researcher that took the interviews and the researcher who scored the audio taped interviews sometimes gave inaccurate scores. For the CAS and the MS, it was not always possible to determine the score that best fitted the parent's answer. In the CAS especially in items concerning different activities it was not always clear how to relate those activities into one score. Because the CAS is a six-point ordinal scale, it was also possible to look at the size of the differences found. In our study, the size of the differences found in the CAS was 1 point in more than 80% of the differences. This means that the score in the first interview was just above or below the score in the second interview, the smallest possible difference. In the MS it was sometimes difficult to determine how to score the equipment used. For example, an electric toothbrush is not a modification as meant, but it is when a parent chooses to use an electric toothbrush for their child because of its functional limitations.

Differences found in retesting after a short period of time showed a decrease in independence in the self-care domain, while in the social function domain most differences showed an increase in independence and in the mobility domain both were found. In case of differences between two parents of the same child, mothers judged their child as more independent than fathers did, especially mothers of disabled children.

Cronbach's alpha was computed on the sample of 63 non-disabled children; for the self-care domain α = .89, for the mobility domain α = .74 and for the social function domain α = .87.

Discussion

The purpose of this study was to examine the reliability of the Dutch PEDI. Intra-class correlation coefficients and Cronbach's alphas were high; therefore, reliability was found to be good, and by considering not only scales but also individual items we could improve some items.

For the American PEDI Cronbach's alpha was computed on the normative sample (*n* = 410) that was made up of children aged between six months and seven years and six months[1]. For the Functional Skills Scale alpha was .99, .97 and .98 for the self-care, mobility and social function domains, respectively. Our results are not completely comparable: we controlled for development by computing alpha on a sample that was homogeneous for age, and we found lower alphas (.89, .74 and .87 respectively). Dutch research with children of other ages will have to confirm the high alphas of the American PEDI.

In our study inter-interviewer reliability was greater than test-retest reliability, and both were greater than inter-respondent reliability. Other researchers[4,5] found the same results for test-retest and inter-respondent reliability, although their methods were slightly different from ours. We feel that differences between first and second measurement are due to a test-effect: parents mentioned that as a result of the first measurement they watched the performances of the child and their assistance more consciously. In a Swedish study[8] the Functional Skills Scale was administered as a written questionnaire and the other scales were administered as an interview: although they concluded that this did not reduce interview time sending a list with the subjects to be discussed may be a way to increase reliability by focusing attention on these subjects before the parents are interviewed.

In all parts of this study, except for internal consistency, the mobility domain scored better than the self-care and social function domain. An explanation for this finding might be that items of the mobility domain, more than in other domains, are less subjected to choices parents make when raising their children. For example, *'carrying small objects'* (mobility, item 35) is different from '*using a knife'* (self-care, item 9) where the choice of parents whether or not to let their child practise with a knife is, in some age groups, the main explanation for the score 'capable' or 'not capable'.

Both researchers scored inaccurately while they were interviewing and scoring; therefore, we do not think this is an interviewer effect. Test length might be a factor that can partially answer the question: the PEDI consists of 241 items. Despite the fact that only a part of the 201 Functional Skills Scale items are offered, the PEDI-interview lasts about 45 to 60 minutes and it must be difficult to be totally concentrated all that time. Furthermore, parents do not always answer in accordance with the scoring criteria and more information is required than a simple 'capable' or 'not capable' to be sure that the parent has understood the question well and the child meets the scoring criteria. Sometimes, this leads to answers other than those initially given. This is also why administration of the PEDI as a written questionnaire did not reduce the interview time[8]. Respondents in the content validity study[7] also mentioned the length of the test as a possible disadvantage of the PEDI, but did not want to remove items.

In the inter-respondent study it became clear that parents differ in their judgement of the functional status of their child. Mothers judged their children more capable and less dependent on their assistance than fathers did, especially when the child is disabled. This may be because the mother spends more time taking care of their children. We cannot conclude that the judgement of the mother is better than the judgement of the father, just because the mother spends more time with her child. But when the PEDI is used for evaluative purposes, it seems important to interview the same parent to ensure that differences between two measures are the result of real changes in functional status rather than the result of differences in judgments between parents.

In conclusion, the Dutch PEDI can be used in further research to establish validity, in computing standardized scores for the Dutch population and finally in paediatric rehabilitation practice.

Clinical messages

- The Dutch PEDI is a reliable instrument to measure functional outcome in Dutch children.
- In using the PEDI as an evaluative instrument it is important to consequently interview the same parent to be sure that differences found are not due to differences in judgments between parents.

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Chapter 4

Discriminative validity of the Dutch 'Pediatric Evaluation of Disability Inventory' (PEDI)

J.W.H. Custers[1], J. van der Net[1], H. Hoijtink[2],

J.E. Wassenberg-Severijnen[3], A. Vermeer[3] en P.J.M. Helders[1]

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[1]Department of Pediatric Physiotherapy, University Medical Center/Children's Hospital Utrecht, the Netherlands

[2]Department of Methodology and Statistics, Faculty of Social Sciences, Utrecht University, the Netherlands

[3]Institute for the Study of Education and Human Development, Utrecht University, the Netherlands

Abstract

Objective: To examine the discriminative validity of the Dutch Pediatric Evaluation of Disability Inventory (PEDI) to differentiate functional status between children with and without disabilities.
Design: Cross-sectional study.
Setting: A university children's hospital in the Netherlands
Participants: A clinical sample comprising 197 children with disabilities (infantile encephalopathy, n= 40; juvenile idiopathic arthritis, n= 20; neurometabolic disorders, n=36; neuromuscular disorders, n= 9; skeletal disorders, n= 28; spina bifida, n= 41; traumatic injury, n= 23), and 62 children without disabilities.
Interventions: Not applicable.
Main Outcome Measure: Functional status was measured by using a Dutch version of the PEDI.
Results: Discriminant analysis established the sensitivity and specificity of the PEDI. Correct predictions of group-membership (disabled vs. non-disabled) were found in both children without disabilities (93.5% correctly predicted) and children with disabling conditions (91.6% correctly predicted).
Conclusion: The discriminant validity of the Dutch PEDI between children with and without disabilities was excellent.

Key words: Disabled children; Rehabilitation; Reliability and validity.

Introduction

The 'Pediatric Evaluation of Disability Inventory' (PEDI), developed by Haley et al.[1,2] is a clinical assessment of functional status in children from 6 months to 7½ years of age. It is a judgement-based structured interview for parents used by professionals in rehabilitation medicine and in health related outcome research. The PEDI measures both *capability* (what the child can do) and *performance* (what the child actually does do) of routine daily childhood activities. It is comprised of 3 content domains – self-care, mobility, and social functioning – and results in 6 outcome scales.

A main goal of the PEDI is to detect whether a deficit or delay exists in children with respect to the functional status development and, if so, the extent and content area of the delay or deficit. The PEDI can be viewed as a discriminative outcome instrument according to the classification of Kirshner and Guyatt[3]. Feldman et al. [4] examined the construct validity of the PEDI's discriminative power. They compared the outcome of the PEDI between 20 children with disabilities, that is, children with arthritic conditions and spina bifida, and a matched normative sample. The children with disabilities scored significantly lower than the children without disabilities in the self-care and mobility domains. Although the results confirmed the potentials of the PEDI to discriminate, it was based on a small sample size. Other kinds of validity studies and reliability studies have been published[1,5-8] with the original PEDI.

The applicability of the PEDI in the Dutch society was examined in a preliminary study[9]. PEDI scores of Dutch children without disabilities were compared with the scores of American peers. The results showed different outcome profiles, indicating possible inter-cultural differences. A Dutch translation and adaptation of the PEDI[10] was subsequently conducted based on current scientific guidelines in cross-cultural research[11-13]. Four new items were added to the original PEDI, whereas some of the 197 existing items were adapted or reformulated to better fit Dutch society. Examples of these adaptations are the conversion of weights and measures into the metric system and the addition of a shower to the items concerning tub transfers. No items were eliminated from the original PEDI. The researchers of the original PEDI authorized the content of the Dutch PEDI. At the moment, the Dutch PEDI still has to be calibrated for Dutch children in the age group from 6 months to 7½ years.

In this study, we examined the discriminant validity of the Dutch PEDI to complete this adaptation process. Children with and without disabilities were included, and discriminant analysis was used to examine whether the Dutch PEDI was able to correctly identify children with functional deficits. The choice of the clinical sample was based on the assumption that a broad spectrum of functional limitations, physical and/or intellectual, was needed to capture the whole PEDI

content. Therefore, we included children with central nervous system (CNS) impairments and children with musculoskeletal impairments. Regarding the first group, we included children with a known psychomotor delay, spina bifida, or infantile encephalopathy. It was assumed that functional limitations would be found in the physical as well as the cognitive domains of the PEDI in the children with CNS involvement because intellectual impairments are not uncommon in these patient groups. In addition, children with juvenile idiopathic arthritis, osteogenesis imperfecta, traumatic injury, and neuromuscular disorders represented the children with musculoskeletal involvement. In these children, it was assumed that functional limitations would be found mainly in the ambulation and self-care skills. Although it was not the main purpose of the study, we also looked at differences between the clinical groups.

Methods

Participants

Between August 1999 and November 2000, 62 children without disabilities were recruited from a health care centre for infants and toddlers (table 4.1). Parents visited this outpatient clinic for routine health assessment of their child. A clinical sample was measured between January 1999 and October 2000, comprising 197 children with different kinds of disabilities (table 4.1). Of them, 166 children were recruited from the University Children's Hospital and from an affiliated rehabilitation centre, whereas the other 31 children were recruited from a study in children with infantile encephalopathy. All children were approached after their visit to the outpatient's clinic within the given time frame of the study.

Table 4.1 Patient characteristics.

	Age (mo)	Age (mo)	Boys	Girls	Total
NMC	35.2 ± 17.8	10-87	22	14	36
SB	42.9 ± 25.6	10-89	18	23	41
Skeletal	58.1 ± 23.5	23-90	13	15	28
Encephal	64.7 ± 17.2	23-90	28	12	40
JIA	39.0 ± 21.5	14-88	6	14	20
Trauma	44.0 ± 21.1	10-84	13	10	23
NMD	70.4 ± 12.5	49-84	5	4	9
Total with disability	49.0 ± 23.8	10-90	105	92	197
No disability	30.6 ± 3.8	24-35	26	36	62
Total			131	128	N=259

NOTE: Values are mean ± standard deviation, range, or n.

Abbreviations: NMC, neurometabolic conditions; SB, spina bifida; Skeletal, skeletal disorders; Encephal, infantile encephalopathy; JIA, juvenile idiopathic arthritis; NMD, neuromuscular disorders.

The clinical sample comprised 7 diagnostic groups (table 4.2). The children were previously diagnosed, with the exception of the children with symptoms of a neurometabolic disorder. These children, in whom there was not always a diagnosis at hand, presented different levels of psychomotor delay, sometimes associated with seizures, muscular conditions, failure to thrive, and sensory impairments. Children and parents were excluded if they were not able to actively use the Dutch language. This was determined at the introduction of the study when they were not able to iterate what they were told about the procedure.

Table 4.2 Clinical samples characteristics of diagnosed patients.

Clinical group	Subtype			
SB* (n = 41)	Thoracic lesion (n = 7)	Lumbar 1-3 lesion (n = 8)	Lumbar 4-5 lesion (n = 15)	Sacral 1-2 lesion (n = 11)
Skeletal (n = 28)	OI type I (n = 17)	OI type III (n = 5)	OI type IV (n = 4)	Achondroplasia (n = 2)
Encephal (n = 40)	Hemiplegia (n = 21)	Diplegia (n = 14)	Quadriplegia (n = 4)	Others (n = 1)
JIA (n = 20)	Monoarticular (n = 2)	Oligoarticular (n = 11)	Polyarticular (n = 4)	Systemic (n = 3)
Trauma (n = 23)	Upper extremity (n = 9)	Lower extremity (n = 12)	Neurotrauma (CNS) (n = 2)	
NMD (n = 9)	Anterior horncell (n = 1)	Peripheral nerve (n = 3)	Muscular (n = 5)	

Abbreviation: OI, osteogenesis imperfecta.

* Spina Bifida with myelomeningocèle (n=41) and shunted hydrocephalus (n = 39).

Instrument

The child's functional capability was measured by using 3 functional skills scales of the Dutch PEDI[1,4]. These scales contain a total of 201 questions organized within 41 subscales concerning 3 domains: self-care domain, mobility domain, and social function domain (table 4.3). Each question is scored positive (score 1) or negative (score 0). A positive score was given when a child had mastered the particular skill. Raw scores for each subscale and per domain were summed.

The child's performance was measured by using 3 caregiver assistance scales of the Dutch PEDI[1,4]. These scales contain 20 questions concerning the same activities of the functional skills scales (table 4.4). The amount of assistance is scored on a 6-point ordinal scale. Scores of 0 and 1 refer to the supportive participation of the caregiver for more than half of the activities, whereas scores of 2 to 5 refer to a progressive independence of the child. Raw scores were summed for each domain.

Table 4.3 Item content of the Dutch PEDI to determine functional capability.

Self-Care Domain[a]	Mobility Domain[b]	Social Function Domain[c]
Types of food textures	Toilet transfers	Comprehension of word meanings
Use of utensils	Chair/wheelchair transfers	Comprehension of sentence complexity
Use of drinking containers	Car transfers	Functional use of communication
Tooth brushing	Bed mobility/transfers	Complexity of expressive communication
Hair brushing	Tub transfers	Problem-resolution
Nose Care	Indoor locomotion- methods	Social interactive play
Hand washing	Distance/speed indoors	Peer interactions
Washing body and face	Pulls/carriers objects	Play with objects
Pullover/front-opening garments	Outdoor locomotion- methods	Self information
Fasteners	Distance/speed outdoors	Time orientation
Pants	Outdoor surfaces	Household chores
Shoes/socks	Upstairs	Self protection
Toileting tasks	Downstairs	Community function
Management of bladder		
Management of bowel		

[a] Self-care domain: 74 questions in 15 subscales
[b] Mobility domain: 61 questions in 13 subscales
[c] Social function domain: 66 questions in 13 subscales

Table 4.4 Item content of the Dutch PEDI to determine performance.

Self-Care Domain[a]	**Mobility Domain[b]**	**Social Function Domain[c]**
Eating	Chair/ toilet transfers	Functional comprehension
Grooming	Car transfers	Functional expression
Bathing	Bed mobility/transfers	Joint problem solving
Dressing upper body	Tub transfers	Peer play
Dressing lower body	Indoor locomotion	Safety
Toileting	Outdoor locomotion	
Bladder management	Stairs	
Bowel management		

[a] Self-care domain: 8 subscales
[b] Mobility domain: 7 subscales
[c] Social function domain: 5 subscales

Procedure

Five experienced clinicians, chosen for their expertise on the relevant patient groups, interviewed the parents. The interviewers completed a training program according to the guidelines of the PEDI manual[1]. All parents (N= 259) who participated in the study gave informed consent. The Dutch PEDI was administered at home or in the hospital in 105 cases, 154 interviews were administered by telephone. To improve validity, we administered the PEDI to the person who provided the most care for the child. This decision was left to the caregivers and was subsequently reported.

The parents of children with juvenile idiopathic arthritis were interviewed within a month after they visited the outpatient department for the first time. Because symptoms may vary from day to day in children with JIA, we standardized the interview by asking the parents to base their judgement on the past 14 days. Parents of children with a traumatic injury were interviewed within 14 days after the incident, and they were asked to base their judgement on the actual functional status. All other interviews were performed during their visit to the outpatient department or within 1 month.

Data Analysis

Based on an analysis of covariance[14], age-corrected scale scores were computed for each of the 6 outcome scales (3 functional skills scales and 3 caregiver-assistance scales). This was necessary to correct for age differences among the eight groups (table 4.1).

Discriminant validity was examined by using discriminant analysis after we established the reliability and item-test correlations of each of the 6 outcome scales (which were around .94 and .78, respectively). Discriminant analysis was conducted by canonical discriminant functions and was used to predict a child's group membership by using his/her 6 age-corrected scales scores. The SPSS statistical program, version 7.5[a], was used for the analysis.

Results

Table 4.5 presents the resulting cross-tabulation of observed and predicted group membership. The diagonal (bold) represents the amount of correctly identified children in their respective (clinical) groups based on the PEDI outcome. We found that 93.5 % of the children without a disability were correctly predicted as being non-disabled, and 8.4% of the children with a disability were predicted as not having a disability, that is, 91.6% of the children with a disability were correctly predicted as being disabled.

When clustering diagnostic groups with a known CNS involvement (psychomotor delay, spina bifida, infantile encephalopathy) and diagnostic groups with a known musculoskeletal involvement (juvenile idiopathic arthritis, osteogenesis imperfecta, traumatic injury, neuromuscular disorders), discriminant analysis showed comparable high prediction rates, that is, 76.0% and 67.5%, respectively, as can be seen in table 4.6.

Table 4.5 Classification results.

	Predicted group membership								
Observed	No disability	NMC	SB	Skeletal	Encephal	JIA	Trauma	NMD	Total
No disability	**93.5**	1.6	0.0	1.6	0.0	3.2	0.0	0.0	100
NMC	5.6	**75.0**	0.0	0.0	8.3	8.3	0.0	2.8	100
SB	4.9	24.4	**39.0**	7.3	7.3	2.4	7.3	7.3	100
Skeletal	10.7	3.6	7.1	**21.4**	17.9	21.4	14.3	3.6	100
Encephal	10.0	22.5	10.0	5.0	**42.5**	2.5	5.0	2.5	100
JIA	10.0	5.0	10.0	0.0	0.0	**50.0**	5.0	20.0	100
Trauma	17.4	8.7	4.3	4.3	8.7	4.3	**43.5**	8.7	100
NMD	0.0	0.0	0.0	0.0	11.1	22.2	22.2	**44.4**	100
All disability	**8.4**								

NOTE: Predicted group membership in percentiles.

Table 4.6 Classification results.

	Predicted group membership			
Observed	No disability	CNS	MSI	Total
No disability	**93.5**	1.6	4.9	100.0
CNS	6.8	**76.0**	17.2	100.0
MSI	11.3	21.2	**67.5**	100.0

NOTE: Predicted group membership in percentiles.
CNS includes psychomotor delay, spina bifida and infantile encephalopathy.
Musculoskeletal involvement (MSI) includes skeletal disorders, juvenile idiopathic arthritis, traumatic injury, and neuromuscular disorder.

Figures 4.1 and 4.2 show standardized means of the 6 subscales used to examine the relative differences in functional status among the respective groups.

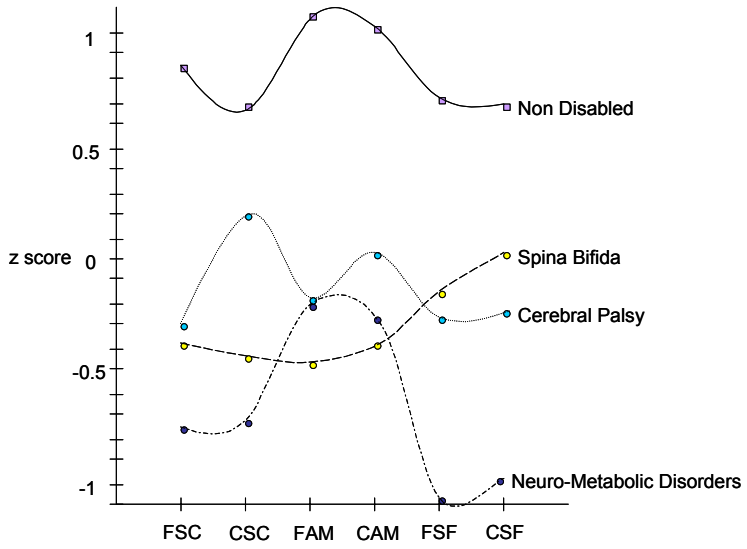

Figure 4.1 Standardized scores for age-corrected scales for patients with CNS involvement.
Abbreviations: FSC, functional skills scale: selfcare domain; CSC, caregiver assistance scale: selfcare domain; FAM, functional skills scale: mobility domain; CAM, caregiver assistance scale: mobility domain; FSF, functional skills scale: social function domain; CSF, caregiver assistance scale: social function domain

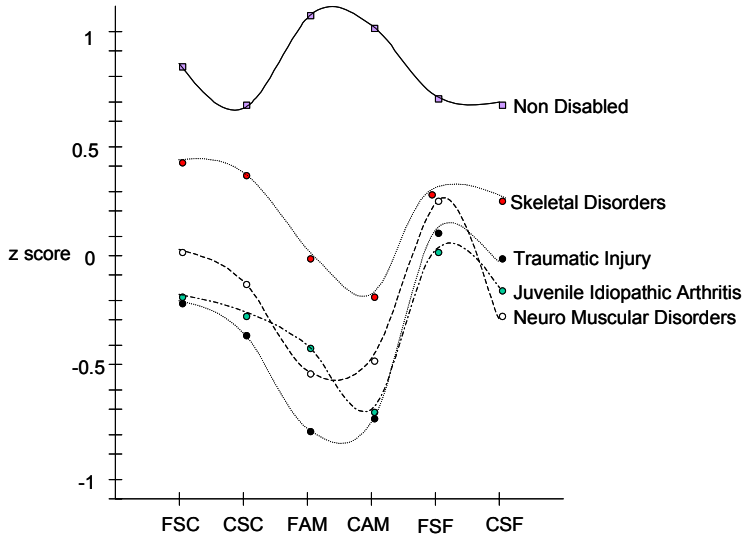

Figure 4.2 Standardized scores for age-corrected scales for patients with musculo-skeletal involvement.

Abbreviations: FSC, functional skills scale: selfcare domain; CSC, caregiver assistance scale: selfcare domain; FAM, functional skills scale: mobility domain; CAM, caregiver assistance scale: mobility domain; FSF, functional skills scale: social function domain; CSF, caregiver assistance scale: social function domain

The standardized means from the children without a disability were higher for all 6 subscales of the PEDI.

Discussion

The aim of discriminative measures is to distinguish between individuals or groups on underlying dimensions[3]. Discriminative measures in rehabilitation medicine are useful to determine the impact of a disorder with respect to functional status at a single point of time. The purpose of this study was to examine the discriminative validity of the Dutch-adapted PEDI, that is, the ability of the Dutch PEDI to discriminate between children with and without disabilities with respect to functional status. This question was solved by using discriminant analysis. However, we first performed an analysis of covariance and computed age-corrected scale scores, because discriminant analysis could not be conducted in this study with children of the same age because the sample sizes were too small.

Because 93.5% of the children without disabilities were correctly predicted as being non-disabled (based on the PEDI outcome) and 91.6% of the children with disabilities were correctly predicted as being disabled, we concluded that the Dutch PEDI's discriminative validity is excellent between children with and without disabilities. Our findings confirm a high degree of sensitivity (correct identification of children with disabilities within this population) and specificity (false prediction of children without disabilities who were identified as disabled).

In our study we were unable to compare the differences between patient groups, mostly because of the lack of homogeneity in the sample base, varying degrees of disease severity within a group, and lack of data on the intellectual skills of the children. However, 2 major groups were distinguished, and thereby a high percentage of the children with CNS and musculoskeletal involvement could be correctly predicted (table 4.6). This is also shown in figure 4.2, which presents similar *z*-score profiles of patient groups with a musculoskeletal involvement, in contrast to the patient groups with a CNS involvement (figure 4.1). This is at least suggestive for further support of a good discriminant validity of the Dutch PEDI. Future studies are needed to establish the discriminative validity of the PEDI between homogeneous but different diagnostic groups.

Conclusion

This study confirmed that the Dutch PEDI has excellent discriminative validity with respect to functional status of daily activities of children with and without disabilities. The results establish the applicability of the PEDI for discriminative purposes in the patient groups used in this study. Therefore, the PEDI can serve as a diagnostic tool for professionals in pediatric rehabilitation medicine.

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Chapter 5

Standardization of the Dutch 'Pediatric Evaluation of Disability Inventory' (PEDI)

J.E. Wassenberg-Severijnen[1], C.J.M. Maas[2], J.W.H.Custers[3], P.J.M. Helders[3], A. Vermeer[1], H. 't Hart[2]

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[1]Institute for the Study of Education and Human Development, Utrecht University, the Netherlands

[2]Department of Methodology and Statistics, Faculty of Social Sciences, Utrecht University, the Netherlands

[3]Department of Pediatric Physiotherapy and Exercise Physiology, University Medical Center and Children's Hospital Utrecht, the Netherlands

Abstract

The Pediatric Evaluation of Disability Inventory (PEDI), originally developed for the North-American pediatric population, is meant to determine functional status in children aged between 6 months and 7.5 years. After adapting the PEDI for the Netherlands and determining its reliability and validity, a sample of 1849 Dutch children was taken to determine reference values. In this paper the sampling process is described. The sample was representative for current Dutch society with respect to age and gender. Although the sample was not representative with respect to the educational level of parents, no influence on the resulting reference values is expected because the correlation between educational level and PEDI sum scores is very low. The same applies to community size and ethnic origin. Therefore, the resulting normative standard scores can be used in Dutch pediatric rehabilitation practice to measure the deficit or delay in the development of functional status, and if so, the extent and content area of this deficit or delay. Carefully interpreting scores of originally non-Dutch children is recommended as these children were hardly represented in the Dutch normative sample.

Introduction

Measuring aspects of quality of life being important indicators of health outcome, next to biomedical parameters, is becoming increasingly important all over the world. Instruments that proved to be reliable and valid in one country can also be used in other countries to save resources needed for the development of a new instrument. Of course, a translation is needed from the original language into the target language. However, when the aspect to be measured has a cultural component, a simple translation may not be sufficient: a cross-cultural adaptation and a subsequent re-standardization are than recommended. We adapted the PEDI for the Dutch situation and in this paper we describe the last part of this procedure.

PEDI

The 'Pediatric Evaluation of Disability Inventory', originally developed for the US population[1], measures functional status in children aged between six months and seven and a half years, divided in fourteen age groups of half a year each. The PEDI is based on an adaptation of the ICIDH-model of disablement[2]. In the model used for developing the PEDI 'functional limitations' bridge impairment and disability. Impairments are problems in body function or structure; functional limitations are limitations in the ability to perform normal daily activities, whereas disability refers to problems in the performance of those daily activities. The model has been made suitable for use in pediatric rehabilitation by adding a developmental and a contextual framework.[3] Both the capability of the child and the amount of help they get from their parents as well as the equipment used in daily tasks are measured by a structured interview with a parent of the child. This is a quick method for gathering information about the various aspects of the functional status of the child: within an hour 42 topics, varying from the kind of food the child is able to eat and including whether he is capable of saying his own name, are being asked for. Functional status is determined in three domains: Self Care, Mobility and Social Function[a]. Table 5.1 gives an overview of topics of the PEDI adapted for the Netherlands (PEDI-NL).

[a] Although using the same word 'function' in both the aspect to measure and a domain that is part of this aspect is methodologically incorrect, we did not alter the words because of compatibility with the terminology the American authors use.

Table 5.1 Topics in the PEDI-NL.

Self care	Mobility	Social function
Types of food textures	Indoor locomotion methods	Comprehension of word meanings
Use of utensils	Indoor locomotion – distance/speed	Comprehension of sentence complexity
Use of drinking containers	Indoor locomotion – pulls/carries objects	
Tooth brushing		Functional use of communication
Hair brushing	Up stairs	
Nose care	Down stairs	Complexity of expressive communication
Hand washing	Toilet transfers	
Washing body and face	Chair/Wheelchair transfers	Self information
Pullover/front-opening garments	Tub transfers	Problem-resolution
Fasteners	Bed mobility/transfers	Playing with adults
		Peer interactions
Pants	Outdoor locomotion methods	Play with objects
Shoes/socks	Outdoor locomotion – distance/speed	Time orientation
Toileting task	Outdoor surfaces	
		Self protection
Management of bladder	Riding a bicycle	
Management of bowel		Community function
	Car transfers	

The 205 dichotomous items in the Functional Skills Scale (FSS) measure capability, and are scored either 'capable' or 'not capable'. The Caregiver Assistance Scale (CAS, 20 items), measuring the amount of assistance the parent gives the child in performing daily functional activities, is an ordinal six point-scale, ranging from 'totally dependent' to 'totally independent'. The Modification Scale (MS, 20 items), measuring the equipment used, is also an ordinal scale.

An example of an item from the Functional Skills Scale is Mobility item 58*:*

Item 'Does the child ride a bicycle for at least 10 meters on a bicycle with side-wheels?'

Explanation 'The child is capable of getting up and from the bike without any help and to ride the bicycle independently. '

The PEDI has proven to be a reliable and valid instrument[4-7] to measure functional status in the United States. For use in the Netherlands, the PEDI has been translated and cross-culturally adapted. Adaptation was necessary because the environment in which children live in the Netherlands is not identical to the environment in which children in the United States of America grow up, resulting among others in a different order of item difficulty in both countries[8]. In the adaptation process, criteria of the European Research Group on Health Outcomes

(ERGHO) on cross-cultural adaptation were applied: content equivalence, semantic equivalence and conceptual equivalence[9]. The Dutch version of the PEDI was judged by 31 health professionals to determine content equivalence; 8 items were added containing functional skills that are relevant in the development of Dutch children (for example eating with knife and fork, and riding on a bicycle). Other items were reformulated to avoid multiple interpretations[10]. Inter-interviewer, intra-respondent and inter-respondent reliability of this instrument varied from excellent to good in a sample of 53 children with disabilities and 63 children without disabilities[11]. Validity of the PEDI-NL was studied, first to see if this instrument could discriminate between children with and without disabilities: in more than 90% of the children having functional limitations was correctly predicted[12]. Second, responsiveness to change was studied in individual patients and found to vary from moderate to excellent[13]. To complete the adaptation process we calibrated the PEDI for the Netherlands on a large sample of children without known disabilities. In this paper we describe the sampling process, the sample itself, and the meaning of the resulting normative scores.

The manual of the US PEDI[1] describes two kinds of summary scores: Normative Standard Scores and Scaled Scores. The Normative Standard Scores are transformed scores that depend on the age of the child and are used to compare individual scores of children with those of age mates to see whether a deficit or delay in the development of functional status is present, and if so, to what extent and in which content area. Scaled Scores give an indication of functional performance independent of age and can be used to determine changes in functional status after a period of time.

Finally, with the aid of a computer program, goodness-of-fit tests can be performed on the original PEDI, to see whether the development of a child is consistent with the development of non-disabled children with the same raw score. There is an absence of fit when a child is capable of performing relatively difficult items but not capable of performing relatively easy items, a score pattern typically seen in children with particular disabilities.

The normative group on which the US PEDI norms are based is comprised of 412 children. To be as representative as possible of the population in the United States, researchers strived for a sample with a relative equal age distribution across the age span of six months through 7.5 years, equal representation of girls and boys, distribution of race approximating the population, proportional representation of parent educational levels and appropriate distribution of community size[1].

Methods

Sampling process

For a Dutch sample that is representative for the Dutch population of children aged between 6 months and 90 months, the same guidelines as in the United States were followed. The Netherlands is a small country with more than 16 million inhabitants, in which large differences in functional status between the children living in different parts of the country are not to be expected. Therefore, and because of practical and financial restrictions, we took a sample of the children living in one of the twelve provinces in the Netherlands. The sample was drawn from Utrecht, the province that resembles the entire country most in terms of urbanization[14].

In accordance with the US PEDI the children are divided into 14 age groups of 6 months each. In deciding how many interviews we needed to calibrate reliable norm scores, the variation of scores within each age group was the most important but also an unknown factor. Variation in the US scores could serve as an indication of variation of the scores in Dutch children, but because they were based on small samples we did not use that information. Taking into account both a sufficient number of respondents and a response rate of 17% in the reliability study[11] with a similar design, a random sample of 13,500 children was designed. The sample was taken by the 'Provinciale Entadministratie' (PEA), an organization responsible for carrying out three prevention programs (screening pregnant women, screening newborn babies and vaccination program) throughout the country. For this reason, the PEA manages electronic databases with data of all children living in the Netherlands from which samples can be taken for research purposes. We planned to sample in two sessions because interviewers were limited in the number of interviews they could take within a certain period of time. This gave us also an opportunity to react to response rates in the different age groups by sampling more or less in the next session when necessary. To prevent the same child from being sampled twice we selected for each age group a month of birth of those children and took random samples of children born in these selected months. Parents of these children received a letter from the PEA to ask for cooperation in this study. In this letter the aim of the study and the implications of participation were explained and aspects of privacy were mentioned. Parents were able to react by the Internet, by phone or by mail, giving their name and address and preference for an interview at home or by telephone. After two sample sessions in which parents of 13.500 children received the request to participate, parents of 2250 children reacted (response rate 16.7%), most of them (90%) by returning the answering form by mail. Parents of 2250 children reacted and we interviewed 1849 of them. The parents of the other children moved, gave incorrect telephone numbers or did not answer the phone. Also, parents refused to participate on second thoughts or were not able to answer

questions due to lack of knowledge of the Dutch language. In other cases the child passed the age-limit of 7.5 years, or the child had disabilities in daily functioning.

Participants

Children were between 6 and 90 months of age (mean 46.3, SD 22.3 months), almost as many boys (49.7%) as girls. The children grew up in families with 1 – 7 children: 15% of the children did not have brothers or sisters, 52% of the children had one brother or sister, and the others had 2 or more siblings. In 270 families the parent was interviewed for two different children. In table 5.2 there is an overview of the number of children the PEDI was administered to, showing number and gender of the children in each age group.

Table 5.2 Distribution of the Normative Sample by Age and Gender.

Age (months)	*Female (%)*	*Male (%)*	*Total number*
6-11	56.8	43.2	95
12-17	48.2	51.8	112
18-23	47.8	52.2	157
24-29	44.9	55.1	138
30-35	48.4	51.6	155
36-41	52.8	47.2	161
42-47	53.0	47.0	166
48-53	57.4	42.6	162
54-59	53.8	46.2	143
60-65	43.8	56.2	137
66-71	41.7	58.3	103
72-77	51.9	48.1	104
78-83	52.5	47.5	122
84-89	48.9	51.1	94
Total number	930	919	1849

Respondents were most mothers (93%) who share taking care of the children with a partner. Most of the interviews (58%) were held at home with the parent, others were held by telephone. Parents could express a preference of how they wanted to be interviewed, and parents who did not have a preference were randomly assigned to a face-to-face or telephonic interview.

Table 5.3 Ethnic groups in the Netherlands, in Utrecht and in the sample.

	Netherlands (%)[14]	*Utrecht (%)*[14]	*Sample (%)*
Dutch	91.3%	89.8%	96.2%
Non-western immigrants	9.7%	10.2%	3.8%

Ethnic group to which the child belonged (table 5.3), educational level of the parent (table 5.4) and size of the community in which the child grew up (table 5.5) are shown, not only for the sample, but also for Utrecht and the Netherlands.

Table 5.4 Educational level of parents in the Netherlands, in Utrecht and in the sample.

	School types used in the Netherlands	*Netherlands (%)*[#]	*Utrecht (%)*[#]	*Sample (%)*
Low	Lower education	8.7	9.5	0.6
	Mavo	6.3	6.7	5.4
	Vbo	15.0	11.2	3.3
Medium	Havo/Vwo	5.2	5.0	10.2
	Mbo	40.2	30.7	22.1
High	Hbo	16.7	21.8	33.5
	University	7.9	15.1	25.0

[#] : Statistics Netherlands (2002), based on parents aged between 25 and 44 with children living at home

Table 5.5 Community size in the Netherlands, in Utrecht and in the sample.

	Netherlands (%)[14]	*Utrecht (%)*[14]	*Sample (%)*
> 1500 addresses per km^2	41.2%	47.5%	48.4%
1000-1500 addresses per km^2	17.9%	20.1%	17.0%
< 1000 addresses per km^2	40.9%	32.4%	34.5%

The interviews were taken by students (*n* = 49, all but one female) in social sciences, who were trained and had to score a taped interview to prove sufficient knowledge about how to score the PEDI-NL (95% agreement with predefined scores in the FSS, 80% agreement in the CAS, 90% agreement in the MS). They all passed this test. Some interviewers only took 7 interviews, others more than one hundred. The interviewers had to take at least 20 interviews face to face before starting telephonic interviewing.

Analysis

Before computing summary scores we tested scales and structure of the data. Multilevel analysis was performed because of the nested structure of interviewers and families and factor analysis was performed to check the scale structure. We checked for differences in outcome scores between girls and boys, fathers and mothers, and between the different groups related to the education levels of the parents and community size.

If controlling for structure deficits does not show any problems, we will use Rasch analysis to compute standard scores, as was done in the US version.[1] Rasch analysis is used because it provides a framework to test the hypothesized hierarchical one dimensional structure. Latent abilities and item difficulties were estimated for each age group and used as base for the determination of summary scores

Results

In table 5.6 the results of the multilevel analysis are presented: this analysis showed no influence of family but a small yet significant influence of the interviewers. Since children within a family did not resemble each other more than children who are raised in different families on the outcome scores all scores from siblings can be analyzed as if they were independent of each other.

Factor analysis was performed with Mplus: in all scales the first factor accounted for more than 50% of the variance, no negative factor loadings were found and there was a sharp Scree fall between the eigen values of the first and second factor, all implicating that each scale was found to represent one factor, and all items scored high on that factor. This confirms that the structure of the PEDI-NL was the same as it was in the original PEDI. The results of these analyses are presented in table 5.7.

Table 5.6 Multilevel analysis: variance distribution over the different levels.

	level 1 (child)	*level 2 (family)*	*level 3 (interviewer)*
FSS selfcare	98.0%	-	2.0%
FSS mobility	100%	-	-
FSS social func.	97.4%	-	2.6%
CAS selfcare	96.0%	-	4.0%
CAS mobility	98.0%	-	2.0%
CAS social func.	95.0%	-	5.0%

Table 5.7 Factor analysis.

	% variance accounted for by factor 1	*eigen value factor 1*	*eigen value factor 2*	*eigen value factor 3*
FSS selfcare	77.9%	56.838	3.409	1.489
FSS mobility	82.3%	53.530	2.728	1.798
FSS social func.	75.0%	49.551	3.237	1.859
CAS selfcare	65.5%	5.240	2.728	2.000
CAS mobility	72.8%	5.096	2.705	1.731
CAS social func.	84.7%	4.234	0.238	0.224

Table 5.8 presents the independent variables that contribute significantly to the percentage explained variance in PEDI-scores. In all scales and in all domains, age is by far the most important explaining factor in the PEDI. The contribution of gender is in some cases significant, but hardly relevant.

Table 5.8 R square of different independent variables.

Dependent	*Age*	*Age and gender*	*Ethnicity, Parent education, Community Size*
Functional Skills			Not significant in all domains
Self-care	.787	.794	
Mobility	.605	not significant	
Social function	.722	.724	
Caregiver Assistance			Not significant in all domains
Self-care	.799	.804	
Mobility	.669	not significant	
Social function	.647	.649	

Defining reference values

The manual of the US PEDI[1] describes two kinds of summary scores: age dependent Normative Standard Scores and Scaled Scores that are independent of age. Rasch analysis is used to estimate the latent abilities, the functional status, corresponding with the possible summed score, both separate for each age group and for the total sample. The first were used to determine Dutch normative standard scores, the second for the determination of scaled scores. Therefore, they were transformed into easily interpretable scores. It is beyond the scope of this article to show all normative standard scores for 2 scales in 3 domains and 14 age groups: they will be published in the manual of the PEDI-NL[15].

For each age group, normative standard scores have a mean of 50 and a standard deviation of 10, therefore a normative standard score can be directly interpreted in terms of deviation from the mean score in that age group. For example, when a child has a normative standard score of 30, two standard deviations below the mean, it means that more than 95% of the normal developing children have higher scores, and the child could have disabilities in daily functioning.

Scaled Scores give an indication of functional performance independent of age and can be used to determine changes in functional status after a period of time. The Scaled Scores vary from zero to 100: zero means that a child is not capable of performing even the easiest item, 100 means that the child has mastered all the items.

Conclusion and discussion

Purpose of this study was to compute standard scores for the Netherlands based on a sufficient large and representative sample of Dutch children growing up without disabilities and/or restrictions in their daily functioning. After many checks both for the structure of the instrument and possible disturbing variables, we conclude that the reference values based on this sample are an important supplement for the Dutch translation and adaptation of the Pediatric Evaluation of Disability Inventory[1]. The PEDI-NL is based on the US PEDI, and analyses confirmed that the structure of the PEDI-NL is the same as the structure of the original PEDI, despite all the changes that were made during the adaptation into the Dutch PEDI. In this paragraph we will discuss the issues of the representative ness of the sample, striking results as the difference between boys and girls in Self-care, and the question whether re-standardization is necessary in an adaptation process.

As reported earlier, data collection was restricted to one part of the Netherlands, Utrecht. The sample was equally distributed for age and gender, but differed significantly from the Utrecht population in terms of ethnicity, parent education and community size (χ^2-tests, all $p < .01$). Would the reference values be different with a full representative sample? Based on the low correlations between the possible disturbing variables and the PEDI-scores we are convinced that these variables do not affect the PEDI-scores. The correlations between ethnic group, parent education and community size and sum score in the Functional Skills Scale are -.01, -.04 and -.08 respectively. In the sample especially originally non-Dutch parents were underrepresented. This may be the result of a language problem: parents, who do not speak Dutch well, do not meet the inclusion requirements. We felt that interviewing parents who do not sufficiently understand the Dutch language and needing a translation in their original language was not appropriate. Further investigations are needed to look for cultural differences between children with Dutch parents and children with parents originally from other countries and its consequences for using the PEDI-NL.

The non-response in originally non-Dutch parent partially explains the small response rate, nearly 17%, but there are more (possible) explanations. Unfortunately, non-response research was not possible because of privacy constraints. Therefore, these explanations are somewhat tentative. Because parents who cooperated in our study had nothing to gain but scientific progression in

pediatric rehabilitation, especially higher educated parents who are interested in science cooperated in our study. Furthermore, the two samples were drawn by the end of November and May respectively, busy periods for parents with young children because of the December festivities and summer holidays respectively. However, in conclusion, we do not think that these factors have systematically influenced the scores on the PEDI, and therefore also have not influenced the resulting reference values.

There was a small but significant interviewer effect. Although we tried to define the items and explanations in a way that all users interpret them in the same way, a small amount of own interpretation is inevitable. Visual inspection of the mean PEDI-scores per domain per age group showed no signs of systematic deviations in individual interviewers. Because we are interested in determining normative standard scores, not in individual results of children, no corrections were made for this interviewer effect. In the past we already recommended interviewing the same parent again when using the PEDI for evaluative purposes[11]. We can add the recommendation that also the same interviewer will take the interviews. For the original PEDI, unfortunately, no tests on interviewer effects are reported. As shown earlier[11] there are differences between the PEDI-domains in the kind of items they contain, resulting in different reliability scores. In agreement with these findings, we were not surprised by the fact that the Social Function domain has the largest interviewer effect and the Mobility domain the smallest. Items in Mobility are most concrete, therefore least sensitive to interpretations of the interviewer or the parent, whereas Social Function items are less concrete, leaving some room for interpretation of answers. Compare for instance the following items.

Mobility (FSS) item 58:

'Does the child ride a bicycle for at least 10 meters on a bicycle with side-wheels?'

Social function (FSS) item 58:

'Is the child careful with sharp or hot objects?'

The Mobility-skill can be observed by parents, whereas the answer to the Social Function item depends on their interpretation of 'careful' behaviour.

The results presented in table 5.8 suggest significant differences between boys and girls in this sample, both in the Functional Skills Scale and the Caregiver Assistance Scale. Gender explains a very small part in the explained variance in the Social Function domain, but nearly 1% in the Self Care domain. Dutch girls have more skills and perform their daily activities more independent from their parents than Dutch boys do as can also be seen in Figure 5.1. In all age groups except the youngest, boys have lower scores than girls.The US Manual only reports small, non-significant correlations between gender and a summed score of all Functional Skills (Self Care, Mobility and Social Function together). In general, girls in the Netherlands are thought to be more independent than boys are in the Self Care domain and also in the Social Function domain. Because the contribution of gender to the explained

variance was significant but very small and therefore not relevant, we choose not to calibrate different standardized scores for boys and girls.

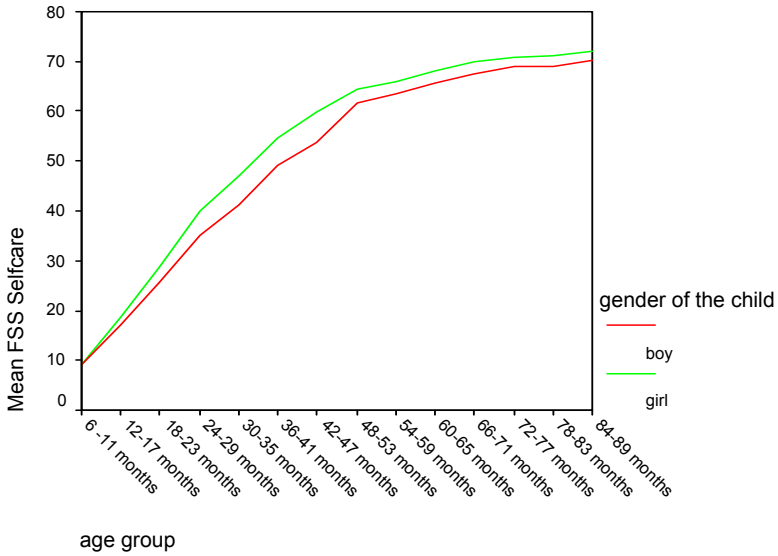

Figure 5.1 FSS Self care for boys and girls.

Re-standardization is in our study the end of the adaptation process that starts with a translation. Not all foreign adapters of the PEDI did choose for an extended adaptation[16,17]. In stead, they used a translation procedure rather than an adaptation procedure. However, the advantages of having specific standard scores for the culture for which the PEDI is adapted have to be weighted against the costs. The more comprehensive the changes that are made during the adaptation, the more re-standardization is needed.

In conclusion: Dutch normative standard scores of the Pediatric Evaluation of Disability Inventory (Dutch version) that can be used to discriminate between children with and without disabilities are established on a large sample that was representative for Dutch society. Also, scaled scores are computed, and with this study the adaptation of the Dutch PEDI is completed.

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Chapter 6

Pediatric Evaluation of Disability Inventory (PEDI): Comparison of the Dutch and original version

J.E. Wassenberg-Severijnen[1], H. 't Hart[2], A. Vermeer[1],

J.W.H.Custers[3], P.J.M. Helders[3]

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[1]Institute for the Study of Education and Human Development, Utrecht University, the Netherlands

[2]Department of Methodology and Statistics, Faculty of Social Sciences, Utrecht University, the Netherlands

[3]Department of Pediatric Physiotherapy and Exercise Physiology, University Medical Center and Children's Hospital Utrecht, the Netherlands

Abstract

The Pediatric Evaluation of Disability Inventory (PEDI) has originally been developed for the North-American pediatric population and has been translated, adapted and re-standardized for use in the Netherlands. Purpose of this study was to determine the equivalence between the adapted and the original Pediatric Evaluation of Disability Inventory (PEDI). *Semantic* equivalence was confirmed by the acceptation of the back translation by the original constructors. *Content* equivalence was determined by Dutch health professionals in a content validity study. Finally, by showing that the structure of the scales, the sum scores and the ranking of the item difficulties in the Dutch and the original version were very similar, *conceptual* equivalence was established. Small differences found confirmed the need for adaptation of this instrument. Dutch pediatric rehabilitation now has an instrument for measuring functional status, an important concept, adapted for the Netherlands and having Dutch reference values.

Introduction

In today's health care, using valid and reliable instruments is necessary both in the care of an individual patient and in program evaluation. In the treatment of individual patients evidence based practice is recommended while policy makers require objective proof of the efficacy of interventions. All over the world researchers put a lot of effort in developing and testing instruments that measure various aspects of health. Researchers who want to measure the same health aspect can take advantage of these efforts by using the instruments that have been developed. By adapting the existing instruments, valuable resources are saved and global comparative studies are possible. A simple translation of these instruments is often insufficient as the aspects to measure are also culturally determined, which is the case in most human behavior: therefore, a cross-cultural adaptation is recommended. After this adaptation process, the equivalence between the original and the adapted version has to be established. In this paper, we report on the equivalence-process of the original and adapted Pediatric Evaluation of Disability Inventory (PEDI). We adapted the PEDI, being originally developed for the United States of America[1], for use in the Netherlands[2-6]. This equivalence research investigated the semantic, the content and the conceptual equivalence obtained for the Dutch PEDI.

Theory and methods

Changes within a discipline usually start with the acceptation of new theories. Pediatric rehabilitation is a rapidly changing discipline: new theories emerged that caused a shift in interventions from the child to his direct environment, and a shift from focussing on impairments to stressing functionality[7] . To be able to use these new insights in practice, instruments for diagnostics and evaluation of interventions that follow these new ideas have to be designed. Sometimes, such instruments have already been developed in other countries and researchers have to decide whether they adapt these instruments or they design their own (new) ones. When no such instruments exist, researchers do not have a choice but to develop a new instrument. By designing a new instrument, it is possible to make it exactly fit to the culture in which it will be used. However, it is also very expensive. Adapting existing instruments takes less time and costs, and by using existing instruments, international comparisons can be made.

Behling and Law[8] argue that there are no universal rules regarding which questionnaires should or should not be translated. The most important consideration is whether the theoretical concept to be measured exists in a near identical form in both the source and target culture. Only when transferability of the concept is defensible, adaptation of the foreign instrument can be considered. Furthermore, only instruments that have been tested for reliability, validity and utility should be

considered for translation and adaptation. Practical problems in translating questionnaires are a lack of semantic equivalence across languages, a lack of conceptual equivalence across cultures and a lack of normative equivalence across societies. Which of these problems is the most prominent in translating an instrument depends largely on the kind of information sought. According to Behling and Law[8], translation of behavioural reports should mainly reveal a lack of normative equivalence, whereas in the translation of instruments measuring attitudes or opinions a lack of semantic equivalence more often occurs. Suggestions for solving semantic problems are adapting instead of simply translating, and performing several back and forward translations by translators who are part of the research team.

The European Research Group on Health Outcomes (ERGHO)[9] stresses content equivalence, together with semantic-, and conceptual equivalence when instruments are cross-culturally adapted. Content equivalence refers to the observation whether the concept of each item is relevant to the cultural setting. Semantic equivalence is aimed at the emphasis that must be placed on retaining the essence of what is being asked or stated rather than obtaining a direct (literal) translation of the words. Finally, conceptual equivalence is when the instrument is found to be measuring the same concept in different cultures. This can be measured by comparing the outcome on specific study populations in the original and target culture.

To meet the criteria of content and semantic equivalence, Guillemin et al.[10] stressed the importance of several forward and back translations performed by qualified, independent, and bilingual translators. Many researchers in this field[9 – 11] stated that a review committee should compare the original and translated versions regarding construct and content of the questionnaire. Such a committee is also likely to modify or eliminate irrelevant, inadequate and ambiguous items and may generate substitutes better fitting the cultural target situation, while maintaining the general concept.

Scandinavian researchers[12] developed comparable guidelines in questionnaire translation. The guidelines consist of four steps: forward translation by several translators, who work parallel, backward translation by an independent professional translator; comparing the different versions and reaching consensus about a final version and finally pilot-testing the final version within the environment where it is supposed to be used.

In conclusion: after having decided what instrument is needed and studying the existence and properties of similar instruments in other countries, researchers should decide if adaptation is possible and recommended. When the concept to be measured is comparable, the instrument is tested thoroughly and before adaptation is decided for, first a professional translation should be made. This translation should be discussed to evaluate functional equivalence and back translated into the original language. After that, the development of the translated version can be finished with pilot testing and eventually determination of reference values for the target culture.

Measuring functional status

The changes in Dutch pediatric rehabilitation forced researchers to develop new instruments that follow these changes. In reviewing existing instruments the PEDI was one of the promising instruments: the PEDI follows the shift towards a functional focus that is incorporated in today's pediatric rehabilitation, its psychometric properties have been found to be satisfactory[13-18] and the important role of the environment is recognized and incorporated as well in the PEDI. Development of independence in daily childhood functioning is not a matter of just maturation: it is also the important role of the environment that leads to differences in this development. And because it is generally recognized that the physical and social environment in the United States of America and in the Netherlands are not identical, differences between American[a] and Dutch children can be expected. Contrary to the United States of America, the Netherlands is a densely populated country where children usually attend school in the neighbourhood they live in. Older children play unattended outside, often in the street they live in, with children of all ages. Many parents work part-time because they are of opinion that being with the child is best for their development. Parents do say that they promote independence, but generally the circumstances described do not allow children to be independent at an early age. Besides this intuitive argument of differences in environment, findings of a preliminary study[19] also indicated cultural differences. In this study, score profiles of 20 healthy Dutch children were compared with those of American peers and found to be incompatible. Therefore, the PEDI was translated by a professional translator and adapted for use in the Netherlands[2]. After that, the reliability of the Dutch PEDI (PEDI-NL) was determined, and additionally discriminative and evaluative properties of the PEDI-NL were studied[3-5]. Finally, new reference values were computed based on a sample of 1849 Dutch children[6].

Equivalence between the Dutch and original PEDI: process and results

Content and semantic equivalence

The concept 'functional status' is thought to be the same in the Netherlands as it is in the United States of America: focusing on the performance of a child in daily childhood functional activities. Therefore, no changes were made to the *construct* of the PEDI: a Functional Skills Scale, Caregiver Assistance Scale and Modification Scale with items divided in three domains Self care, Mobility and Social Function. The original PEDI was based on an augmented model of the International Classification of Impairments, Disabilities and Handicaps and the disablement model

[a] 'America', in this article, refers only to the United States of America.

of Nagi[20]. In the Nagi model, a 'functional limitations' level is added as a bridge between impairments and disabilities. Recently, the World Health Organization has come up with a new classification system, the International Classification of Functioning, Disability and Health (ICF)[21] which is used both in the USA and in the Netherlands. The functionally oriented PEDI fits well in this new classification system[22].

After consulting a group of Dutch health care professionals we slightly changed the content of the PEDI by adding eight items in the Functional Skills Scales (FSS) that represent skills that are essential functional childhood activities in the Netherlands. For example, we added four items about 'riding a bicycle', because children in the Netherlands use their bicycle not only in playing but also to go to school and to sports activities. Although the majority of the consulted professionals judged the PEDI-NL to be long or even too long[2], they agreed that all items fitted in the concept of functional status in the Netherlands. So, content equivalence was established. Furthermore, in the adaptation process all items in the FSS were changed into questions, some items were reformulated to avoid multiple interpretations, others were more consequently divided into an item and a supportive part. Two items in the Caregiver Assistance Scale (CAS) were divided in sub-items because these items contained activities that were hard to combine directly into one score. In addition, we changed the order in which the subjects were presented, especially in 'Mobility' where we grouped indoor activities separately from outdoor activities[1]. After a back translation the constructors of the original test confirmed the semantic equivalence, and gave their permission to use the adapted PEDI in the Netherlands.

Conceptual equivalence

Contrary to semantic and content equivalence, conceptual equivalence can only be established as the adapted instrument is actually used in the target culture. In studying conceptual equivalence, we compared correlations between scales and domains, summed scores and item difficulties in the Dutch and original US version.

The PEDI is based on two major assumptions: changes in functional activities are age-related and the FSS and the CAS represent different dimensions of function. To test these assumptions, the U.S. normative sample was divided into three large age groups: six months until two years, two to five years (preschool) and six to seven-and-a-half years. Using the same division, correlations between age and the different PEDI-scales are given in the appendix, both for the Netherlands and the U.S. normative sample. Comparison between the correlations in the Dutch and U.S. normative sample show remarkable similarity in the youngest age groups. Strength of the correlations among FSS and CAS strongly depends on age: in general, correspondence in younger children is higher than in the older age group. Furthermore, these correlations indicate that as children become older, the areas of capability become more clearly distinguishable: whereas in the youngest group all

scales and domains are highly correlated, in the oldest group the FSS and CAS scores within domains show higher correlations than between domains. Although children living in the Netherlands attend primary school when they are four, dividing the second and third group according to this criterion did not alter the results profoundly. Finally, factor analysis revealed only one factor in each scale and domain, as in the original version. These results strongly indicate conceptual equivalence.

Next, we compared the sum scores corresponding with normative standard scores of 30 to 70. Normative standard scores were originally determined with Rasch analysis for each age group separately and transformed into distributions with a mean of 50 and a standard deviation of 10 to make interpretations easier. A normative score between 30 and 70 (mean $\pm$ 2 standard deviations) represents a normal development in functional status. Table 6.1 shows the results of this comparison for the Functional Skills Scale, table 6.2 shows the results for the Caregiver Assistance Scale[14,23].

Table 6.1 FSS: sum scores corresponding with normative standard scores between 30 and 70 for the Dutch version (*n* = 1849) and *the US version* (*n* = 412).

	Self-care		*Mobility*		*Social function*	
	NL	*US*	NL	*US*	NL	*US*
6-11	3 – 18	*3 – 15*	2 – 25	*4 – 27*	2 – 18	*4 – 22*
12-17	8 – 29	*5 – 34*	10 – 50	*11 – 48*	7 – 32	*6 – 38*
18-23	14 – 40	*16 – 44*	31 – 55	*27 – 52*	17 – 44	*17 – 39*
24-29	21 – 56	*20 – 60*	38 – 59	*39 – 56*	24 – 53	*25 – 48*
30-35	26 – 61	*28 – 63*	45 – 61	*43 – 56*	31 – 59	*28 – 56*
36-41	35 – 66	*31 – 71*	50 – 62	*≥ 48*	36 – 59	*23 – 60*
42-47	40 – 69	*45 – 70*	54 – 63	*≥ 50*	39 – 61	*37 – 60*
48-53	50 – 71	*53 – 71*	57 – 64	*≥ 53*	45 – 63	*48 – 60*
54-59	53 – 72	*57 – 71*	≥ 57	*≥ 55*	47 – 63	*50 –62*
60-65	57 – 72	*53 – 72*	≥ 59	*≥ 54*	48 – 64	*46 – 63*
66-71	58 – 73	*≥ 56*	≥ 61	*≥ 58*	51 – 64	*51 – 64*
72-77	≥ 60	*≥ 69*	≥ 62	*≥ 58*	53 – 64	*≥ 59*
78-83	≥ 61	*≥ 62*	≥ 62	*59*	53 – 64	*≥ 57*
84-89	≥ 64	*≥ 71*	≥ 63	*59*	≥ 55	*≥ 56*

The FSS in the PEDI-NL contained 8 more items than the FSS in the US version: 1 in the Self-care domain, 6 in the Mobility domain (among which the relatively difficult items concerning ‘riding a bike’) and 1 in the Social function domain. In comparing the scores for the Functional Skills Scale some differences can be observed. For example, in the Self-care domain for children aged between 72 and 77 months, US children demonstrate more capacity than Dutch children. However, these differences mainly result from fluctuations that appear not to be age-related, but probably are due to the small U.S. sample.

Table 6.2 CAS: sum scores corresponding with normative standard scores between 30 and 70 for the Dutch version (*n* = 1849) and the U.S. version (*n* = 412).

	Self-care		*Mobility*		*Social funcion*	
	NL	*U.S.*	NL	*U.S.*	NL	*U.S.*
6-11	0 – 2	*0 – 3*	0 – 9	*0 – 11*	0 – 2	*0 – 2*
12-17	1 – 8	*1 – 14*	2 – 21	*2 – 29*	0 – 9	*0 – 12*
18-23	2 – 12	*2 – 19*	11 – 28	*9 – 31*	2 – 21	*2 – 17*
24-29	4 – 27	*4 – 29*	13 – 31	*17 – 33*	5 – 22	*3 – 22*
30-35	5 – 32	*6 – 34*	16 – 32	*18 – 34*	6 – 23	*5 – 24*
36-41	9 – 33	*13 – 37*	20 – 33	*≥ 23*	8 – 24	*7 – 24*
42-47	10 – 36	*18 – 37*	23 – 34	*27 – 34*	10 – 24	*9 – 24*
48-53	13 – 37	*25 – 38*	≥ 27	*≥ 28*	12 – 24	*13 – 24*
54-59	19 – 37	*23 – 39*	≥ 28	*≥ 29*	11 – 24	*≥ 14*
60-65	19 – 38	*≥ 19*	≥ 29	*≥ 31*	≥ 12	*≥ 14*
66-71	23 – 39	*≥ 29*	≥ 30	*≥ 34*	≥ 13	*≥ 16*
72-77	21 – 39	*≥ 27*	≥ 31	*≥ 34*	≥ 15	*≥ 18*
78-83	25 – 39	*≥ 33*	≥ 31	*35*	≥ 15	*≥ 17*
84-89	26 – 39	*≥ 27*	≥ 33	*≥ 32*	≥ 15	*≥ 13*

In the Caregiver Assistance Scale, however, the differences that can be observed are more systematic. For the Self-care and Mobility domain, lower sum scores are considered normal in almost all age groups in the Netherlands than in the U.S.. Contrary to the U.S. sample, reaching independence in all items (score 40) does not fall within the normal range for Dutch children, not even in the oldest age group, indicating that Dutch parents assist their children more than American parents do.

A direct comparison between the Dutch and American reference group is made in a regression analysis with ‘country’ as one of the independent variables. As can be seen in table 6.3 there was no significant influence of country in explaining the scores in the Functional Skills Scale.

Table 6.3 Explained variance by age, gender and country.

Dependent	*Age*	*Age and gender*	*Age, gender and country*
Functional Skills			
Self-care	.784	.789	not significant
Mobility	.562	not significant	not significant
Social function	.730	.731	not significant
	Age	*Age and country*	*Age, country and gender*
Caregiver Assistance			
Self-care	.794	.803	.807
Mobility	.653	.656	not significant
Social function	.657	not significant	not significant

In the Caregiver Assistance Scale, on the contrary, there were significant results, indicating that children in the Netherlands receive more assistance in daily functioning than children in America do in the domains Self-care and Mobility. The increase in percentage explained variance was, however, small.

Finally, we performed analyses comparing the item difficulties in both versions of the PEDI. Both in the original and the Dutch version, the item difficulties were determined using Rasch analyses[6]. Therefore, item difficulties can not be interpreted as absolute numbers, but are relative to the normative sample from which they are derived. Ranking the items from easy to difficult is very similar in both versions in all three domains of the Functional Skills Scale. However, there are some interesting differences. There are skills that American children master earlier in the sequence to independence than Dutch children do, or vice versa. In table 6.4 there is an overview of these items. For the items in which the American ranking is higher than the Dutch ranking it takes more skills for American children than for the Dutch children to master this item.

Table 6.4 Items in the FSS for which the ranking in the Dutch and American PEDI is different (items are ranked from relatively easy to difficult).

Domain	*Short description of the item*	*Rank in the Dutch version*	*Rank in the American version*
Self care	Eats ground foods (item 2)	2	15
	Eats diced food (item 3)	5	21
	Eats all kinds of food (item 4)	18	38
	Prepares toothbrush with toothpaste (item 20)	59	69
	Brushes own hair (item 23)	53	64
	Zips and unzips (item 46)	22	33
	Puts on socks (item 57)	51	39
Mobility	Opens inside and outside doors (item 8)	34	48
	Crawls down the stairs partially (item 19)	35	24
	Crawls down the stairs (item 20)	40	30
	Comes to sit at the edge of the bed (item 41)	42	26
	Gets in and out own bed (item 42)	51	33
	Moves more than 45 meters outside (item 51)	31	42
Social function	Names things (item 11)	17	7
	Calms down when helped facing a problem (item 27)	11	26
	Can wait for help when facing a problem (item 28)	46	36
	Initiates taking care of belonging (item 54)	54	40

Discussion

In this paper we report on our study about the similarities and the differences between the Dutch and the original U.S. version of the Pediatric Evaluation of Disability Inventory. In the Dutch adaptation process, the changes that were made were more than just grammatical while new reference values were determined based on large sample of Dutch children. Although small differences in the resulting outcomes were observed, our results confirmed the equivalence between the two versions. Dutch pediatric rehabilitation now has a reliable and valid instrument for measuring functional status, adapted for use in the Netherlands both in the content and in the subsequent normative standard scores: the PEDI-NL[22]. In this section we will discuss the differences found: how should these differences be interpreted, can they be explained and what is the conclusion regarding these differences? Furthermore, based on our research and our own experiences, we will discuss the translation or adaptation done in other countries.

Besides all the similarities found, there were some small differences between the Dutch and original version, related to the sum scores that represent normal development, and the ranking of certain items in the Functional Skills Scale in the order of difficulty. These differences are probably due to cultural differences between the Netherlands and the United States of America. Items in the PEDI are chosen to represent functional skills and performance that a child aged 7.5 years should be able to master. Differences in sum scores, however, showed that in general Dutch parents assist their children longer than American parents do in performing daily tasks in the Self-care and Mobility domain. In the Self-care domain, normally developing Dutch children do not even reach the stage of total independence. In the Social function domain, no such differences were found. However, caregiver assistance in Social function differs from the caregiver assistance in the other domains. Assistance in Social function is usually not physical assistance, but rather modifications made to adapt to the child's level of communication or cognitive development[1]. When performing tasks like dressing or walking stairs, Dutch parents probably assist their child habitually. When circumstances in the family do not change, they keep on assisting their children, even when they have mastered the necessary skills. Differences between American and Dutch parents may result from different circumstances, as Dutch parents more often (can) make a choice to work less and spend more time with their children.

The results concerning item difficulty show that the order in which functional skills are mastered are different in the U.S. and the Netherlands. It seems that American parents make other choices than Dutch parents do: Dutch parents stimulate their children to eat all kinds of food before they master other functional skills, whereas American parents wait a little longer with ground and sliced food. American parents, on the other hand, permit their children to sleep in an adult sized bed instead of a child's bed at an earlier age than Dutch parents do. In Social

function, the differences in facing problems are interesting. According to the parents, Dutch children are at an earlier age satisfied when helped with a problem, but find it more difficult to wait for help than American children do.

Table 6.5 Age range (in years) at which Dutch and *American* children master the item.

Domain	*Short description*	*> 10%*	*> 25%*	*> 50%*	*> 75%*	*> 90%*
Social function	Gives directions home (item 25)	2.5-3.0 > *3.5-4.0*	3.0-3.5 *4.5-5.0*	4.0-4.5 *5.5-6.0*	4.5-5.0 *6.5-7.0*	6.5-7.0
	Explores familiar setting without adult (item 65)	2.5-3.0 *3.0-3.5*	3.0-3.5 *4.5-5.0*	4.0-4.5 *5.5-6.0*	5.0-5.5 >	5.5-6.0 *6.0-6.5*

Remarkably, the items that were identified as indicating cultural differences between American and Dutch children[19] are not shown in the above list, suggesting that no major differences in ranking were found. However, Table 6.5 shows for two of these items a comparison of the age range at which 10/25/50/75 and 90% of the children master these items: the differences that were expected based on the preliminary study[19] are clearly visible here.

The differences found confirm the need of a cross-cultural adaptation: although the U.S. and Dutch society are both westerly societies there are small but remarkable differences that influence the final standard scores.

Based on the research done, some suggestions can be made to improve the procedure for adapting an instrument designed for a country other than the Netherlands, concerning the description of the target culture. It will be illustrated with research done with the PEDI in other countries. First, researchers should try to describe the cultural elements that are relevant to the phenomenon measured by an instrument developed in another country. This pertains to the elements in the country of origin and in the country in which the instrument will be used. Therefore, it would be great if the developers of the original instrument did the same. Information on important aspects of both the source and the target culture will make comparisons between the cultures possible, resulting in a statement concerning the magnitude of the differences. If there are many differences on important aspects, the transferability of the concept to be measured should be studied more carefully, probably resulting in the adaptation and re-standardization of the instrument. If the differences are small, a simple translation could be sufficient. And by first examining possible cultural differences, the adaptation process can be combined with the translation process immediately. Nordmark, Orban, Hägglund and Jarnlo[24] translated the PEDI for use in Sweden: after applying the PEDI to 52 non-disabled Swedish children, they found some differences in the Social function domain. After finding high correlations between Swedish and American scores, they concluded that ‘cultural discrepancy between the two populations is small’ and therefore, American normative data can be used in Sweden. However, after describing some differences

between Swedish and American parents they conclude that ‘for use in our country, the PEDI might benefit from some modification with regard to such national differences’. Berg et al.[12] translated the PEDI for the Norwegian society. After focussing on the translation process, they finally concluded that the cultural differences urge them to derive Norwegian reference values[25]. Gannotti and Handwerker[26] , on the contrary, used ethnographic triangulation for the cultural validation of the PEDI in Puerto Rico because they were worried about the transferability of the concept of the PEDI. Ethnographic triangulation uses multiple lines of evidence from interviews and observations to describe and evaluate the construct validity of expressions regarding culture. First, interviews are held with a few representatives of different groups that are involved in the cultural phenomenon that is studied. In case of the PEDI, an interview was held with a small group of Puerto Rican parents, teachers and clinicians of children with and without disabilities from different regions, socio-economic status, age and gender to determine the properties of the developmental niche in Puerto Rico. Second, these properties are checked on a larger sample of these groups to see whether there is intra cultural variation, i.e. whether there are several in stead of one developmental niches in one country. Finally, the results are used to evaluate the impact on the PEDI items or on the interpretation of the summary scores. In conclusion: first examining possible differences in culture between the country the instrument was developed for and the country in which it will be used, can guide decisions how to adapt the original instrument and predictions about the influence of these differences in the resulting scores on the instrument can be made. These predictions can be tested after data in the target country are collected.

A second recommendation concerns the translation. For the Netherlands, the PEDI was translated into Dutch by a professional translator[2]. In Sweden and Norwegian, professionals in pediatric rehabilitation made the translation[12,24]. Because many items contain specialized information, health professionals are probably better translators for a culturally adapted instrument than professional translators are. Furthermore, integrating translation and adaptation is much easier to accomplish.

In conclusion: in this paper, we showed the equivalence between the Dutch and original U.S. version of the Pediatric Evaluation of Disability Inventory. The PEDI-NL has proven to be an instrument of great value for Dutch pediatric rehabilitation and is now available for all professionals in this discipline[23].

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Appendix

Correlations among domains: total Dutch normative sample (n = 1849) *and total U.S. normative sample (n = 412)*

	Functional Skills					
Functional Skills	Self Care		Mobility		Social Function	
Self Care	1.0	*1.0*				
Mobility	0.89	*0.91*	1.0	*1.0*		
Social Function	0.94	*0.96*	0.92	*0.92*	1.0	*1.0*
	Caregiver Assistance					
Caregiver Assistance	Self Care		Mobility		Social Function	
Self Care	1.0	*1.0*				
Mobility	0.85	*0.86*	1.0	*1.0*		
Social Function	0.86	*0.90*	0.87	*0.87*	1.0	*1.0*
	Caregiver Assistances					
Functional Skills	Self Care		Mobility		Social Function	
Self Care	0.93	*0.96*	0.92	*0.91*	0.89	*0.89*
Mobility	0.79	*0.83*	0.95	*0.96*	0.85	*0.85*
Social Function	0.87	*0.92*	0.93	*0.91*	0.91	*0.93*

Correlations among domains: and Dutch Infant Group (n = 364) and *US Infant Group (n = 114)*

	Functional Skills					
Functional Skills	Self Care		Mobility		Social Function	
Self Care	1.0	*1.0*				
Mobility	0.84	*0.87*	1.0	*1.0*		
Social Function	0.87	*0.87*	0.87	*0.91*	1.0	*1.0*
	Caregiver Assistance					
Caregiver Assistance	Self Care		Mobility		Social Function	
Self Care	1.0	*1.0*				
Mobility	0.71	*0.78*	1.0	*1.0*		
Social Function	0.70	*0.78*	0.73	*0.79*	1.0	*1.0*
	Caregiver Assistance					
Functional Skills	Self Care		Mobility		Social Function	
Self Care	0.75	*0.79*	0.82	*0.82*	0.73	*0.72*
Mobility	0.69	*0.75*	0.92	*0.91*	0.71	*0.76*
Social Function	0.70	*0.78*	0.84	*0.85*	0.79	*0.81*

Correlations among domains: Dutch 2- 5 years sample (n = 925) and *U.S. 2-5 years sample (n = 181)*

	Functional Skills					
Functional Skills	Self Care		Mobility		Social Function	
Self Care	1.0	*1.0*				
Mobility	0.79	*0.66*	1.0	*1.0*		
Social Function	0.79	*0.74*	0.72	*0.62*	1.0	*1.0*
	Caregiver Assistance					
Caregiver Assistance	Self Care		Mobility		Social Function	
Self Care	1.0	*1.0*				
Mobility	0.72	*0.69*	1.0	*1.0*		
Social Function	0.65	*0.63*	0.58	*0.56*	1.0	*1.0*
	Caregiver Assistance					
Functional Skills	Self Care		Mobility		Social Function	
Self Care	0.87	*0.89*	0.73	*0.63*	0.64	*0.57*
Mobility	0.72	*0.67*	0.81	*0.66*	0.61	*0.57*
Social Function	0.70	*0.69*	0.67	*0.54*	0.73	*0.76*

Correlations among domains: Dutch 5-7.5 years sample (n = 560) and *U.S. 5 – 7.5 years sample (n = 117)*

	Functional Skills					
Functional Skills	Self Care		Mobility		Social Function	
Self Care	1.0	*1.0*				
Mobility	0.38	*0.39*	1.0	*1.0*		
Social Function	0.53	*0.64*	0.30	*0.35*	1.0	*1.0*
	Caregiver Assistance					
Caregiver Assistance	Self Care		Mobility		Social Function	
Self Care	1.0	*1.0*				
Mobility	0.36	*0.45*	1.0	*1.0*		
Social Function	0.42	*0.56*	0.37	*0.43*	1.0	*1.0*
	Caregiver Assistance					
Functional Skills	Self Care		Mobility		Social Function	
Self Care	0.50	*0.62*	0.28	*0.19*	0.29	*0.16*
Mobility	0.34	*0.31*	0.46	*0.11*	0.33	*0.12*
Social Function	0.36	*0.52*	0.26	*0.26*	0.50	*0.36*

Chapter 7

Summary and general discussion

Summary

Pediatric rehabilitation is a rapidly changing discipline: new theories emerged that caused a shift in interventions from the child to his direct environment, and a shift from focussing on impairments to stressing functionality. To be able to use these new insights in practice, instruments for diagnostics and evaluation of interventions that follow these new ideas have to be designed. In some cases, such instruments are already developed in another country and researchers have to decide whether they adapt these instruments or design their own (new) ones. By adapting the existing instruments valuable resources are saved and global comparative studies are possible. A simple translation of these instruments is often insufficient as the aspects to measure are also culturally determined, which is the case in most human behaviour: therefore, a cross-cultural adaptation is recommended. This thesis described the cross-cultural adaptation and subsequent testing for the Pediatric Evaluation of Disability Inventory (PEDI) for the Netherlands. First, the adaptations made and tests for reliability and validity are described. Next, new reference values for the Netherlands are determined based on a large sample of Dutch children. Finally, a comparison is made between the original and the adapted version to determine equivalence.

The PEDI, originally designed for the U.S. population, is used for the assessment of functional status in children aged between 6 months and 7.5 years. Functional status is the extent to which a child is independent of his parents in performing meaningful daily activities. Performance depends on the capabilities of the child: when a child does not have sufficient skills no independent performance is possible and the child needs assistance of their parents. Furthermore, performance depends on the physical and social environment the child lives in. This environment should provide opportunities for the acquirement of the skills needed for an independent performance, at the same time allowing the child the chance of performing independently when it possesses the necessary skills. The PEDI can be administered by a structured interview with the parent or caregiver of the child. Capability is measured with the Functional Skills Scale (FSS) of the PEDI, which contain items that can be scored either 1 (child has mastered the skill in all or most daily situations) or 0 (child has not mastered the skill). Performance is measured with the Caregiver Assistance Scale (CAS): the amount of support the caregiver (parent) provides in normal daily functioning is scored using an ordinal six-point scale. Additionally, the Modification Scale (MS) is a frequency count of the type and extent of regularly used equipment and modifications while performing daily activities. These activities are classified in three domains: Self-care, Mobility and Social Function.

The PEDI was translated and adapted for use in the Netherlands. In the adaptation process eight items were added to the FSS that represent skills that are being viewed as essential functional activities in the Netherlands, such as eating with knife and fork, and riding on a bicycle. Some existing items were adapted to Dutch habits, such as the use of a shower instead of a bath. Furthermore, methodological improvements were made. The resulting PEDI-NL was presented to 31 health professionals for judging the content validity: according to them the PEDI-NL can be used for assessing functional status in Dutch children in order to discriminate between children with and without disabilities and to evaluate progress in functional behaviour. Both reliability and internal consistency, established in small samples of children with and without disabilities, were good.

The PEDI-NL is aimed to be used as diagnostic tool in pediatric rehabilitation to determine the existence of a deficit or delay in the development of functional status exists, and if so, to what extent and in which content area. Discriminative power was confirmed using the PEDI-NL scores of children with various disabilities and without known disabilities. The scores were used to predict whether the child had functional limitation: more than 90% of the predictions were correct.

For calibrating Dutch reference values a random sample of children aged between 6 months and 7.5 years living in the province Utrecht was taken. The PEDI-NL was used to determine the functional capacity and performance of 1849 children developing without known disabilities. Rasch analyses were used to estimate item difficulties and scores that indicate the capability of children independent of age (scaled scores). Rasch analyses were also performed on the data of 14 different age groups of half a year each, resulting in Dutch normative standard scores. The sample was representative for Dutch society with respect to age and gender. However, children from higher educated parents were over-represented and children whose parents originated from other countries, especially non-Western immigrants, were under-represented. Correlations between these variables and the PEDI scores were low, indicating that they did not affect the PEDI scores and the resulting reference values profoundly. Furthermore, we compared the Dutch and U.S. version of the PEDI. Equivalence was shown in the concept measured: the structure of the PEDI-NL was the same as in the original version, and also the ranking of items from easy to difficult showed many similarities. Differences were found in the ranking of the items, indicating another order in which Dutch and American children master particular skills, probably due to cultural differences between the Netherlands and the United States of America.

Instruments measuring important facets of contemporary Dutch pediatric rehabilitation are necessary to support interventions as well as research. By adapting instruments that focus on these aspects but were originally developed for other nations, valuable resources are saved, and still the instruments are specific to our culture. Dutch pediatric rehabilitation now has a reliable and valid instrument for measuring functional status in children with disabilities, adapted for use in the Netherlands both in the content and in the subsequent normative standard scores. It marks an important milestone in the development of a profession.

General discussion

Improving the process

When having to choose whether or not to adapt an existing instrument, it is tempting to start the adaptation immediately by translating the original instrument into the language of choice. However, to determine how well the instrument fits in the target culture, research should be done on the concept to be measured in this target culture and relate the results to information about that concept in the source culture, on the transferability of the concept[1]. In other words: how well does the instrument fit in and reflect the views and standards of the target society. Describing similarities and differences in source and target culture with respect to the concept that is supposed to be measured can direct the decision whether or not adapt the existing instrument and the resulting adaptation process.

Following international guidelines, the original PEDI has been translated into Dutch by a professional translator. She gave a literal translation in which words and phrases were used that are never used by professionals in pediatric rehabilitation and had to be changed by the review committee. In accordance with Scandinavian researchers[2,3], we are now convinced that, under certain conditions, the translation should be done by health care professionals in the field that will use the instrument. In their translation, the essence of the items in the original version can more easily be transposed into the target language than a professional translator without much knowledge of the aspect that is measured ever can.

Ideally, the adaptation phase should be finished before the pre-testing phase is started. However, part of the adaptations made resulted from studying reliability. The version with which the reliability studies were done differed, therefore, from the final PEDI-NL. Differences, however, were small and we expect that the results will even be better when reliability is determined on the final version.

In the development of the PEDI-NL only a small number of (health care) professionals were involved. The PEDI-NL was only available for research purposes until the publication of the manual, the final phase in the process. We might have taken advantage of giving more professionals the opportunity to use the PEDI-NL in their pediatric physiotherapy practice or their occupational therapy practice. Users of the instrument could have given valuable remarks that could have improved the PEDI-NL, because their remarks will differ from the remarks researchers have made.

The sample taken to determine reference values for the target population should preferably be a national sample, not a regional sample. Both we and the original constructors had financial and practical limitations. Therefore, we both had to take a regional in stead of a national sample. Although we have shown that the results of a national sample probably do not differ from the results of our regional sample, a national sample is more convincing.

Importance of developing instruments

In today's health care, using valid and reliable instruments is necessary both in the care of an individual patient and in program evaluation. In the treatment of individual patients, evidence based practice is recommended while policy makers require objective proof of the efficacy of interventions. Pediatric rehabilitation, like many other disciplines, is a rapidly changing discipline: new theories emerged that caused a shift in interventions from the child to his direct environment, and a shift from focussing on impairments to stressing functionality. To be able to use these new insights in practice, instruments for diagnostics and evaluation of interventions that follow these new ideas have to be designed. In some cases, such instruments are already developed in another country and researchers have to decide whether they adapt these instruments or design their own (new) ones. By adapting the existing instruments valuable resources are saved and global comparative studies are possible. However, even the development of an adapted instrument is expensive, but has to be an essential part of a changing discipline.

Advantages of cooperation of different disciplines

In the Netherlands, pediatric rehabilitation research has been initiated in order to evaluate existing and new therapies. At first, projects were mainly the result of local initiatives within one discipline, but more and more research is organized in cooperation networks like PERRIN (Pediatric Rehabilitation Research in the Netherlands) and NetChild. PERRIN, started in 1999, covers research on children with disabilities, especially children diagnosed with CP. NetChild, founded in 2003, is a multidisciplinary network (pediatric physical therapy, rehabilitation medicine and social sciences) for research about children with developmental disabilities. Important reasons for founding these networks are cooperation between disciplines that have the same goals, using mutual knowledge and connecting different investigations, continuity in research, and a complete presentation to organizations that support the research (financially). Within these networks, pediatric rehabilitation research as a whole is more than the sum of its parts. Constructing instruments has special attention within these networks, because the results of studies largely depend on the reliability and validity of the instruments used.

Future of the PEDI-NL

The PEDI-NL provides Dutch pediatric rehabilitation with an instrument to measure the important concept of functional status for discriminative and evaluative purposes. This instrument is culturally adapted, methodologically improved and supplied with Dutch reference values based on a sample that is more than four times larger than the sample on which the original reference values are based on. In this thesis much of the research done in the development of the PEDI-NL is described. Most important challenge for the near future is to assure that the PEDI-NL is properly used. Therefore, we will develop a training procedure in which the most important aspects of using the PEDI-NL will be mentioned.

Related to the use of the PEDI-NL in pediatric rehabilitation practice, there are some issues that need further investigation. In the reliability studies[4], we have examined differences between mothers and fathers in their judgement of the functional performance of their child. This leads to the recommendation to interview the same parent when the PEDI-NL is used for evaluating changes over time. Future research may try to explain these differences. The reliability study[11] also revealed a major problem in scoring the PEDI: differences between the scores of two researchers were most of the time mistakes, probably due to a lack of concentration. It was already mentioned in the content validity study[5] that the PEDI was (too) long, and here the results for the accuracy of scoring are visible. An interview takes about 45 to 60 minutes, and it seems difficult to be concentrated maximally all that time, both for interviewer and respondent. Attempts to solve this problem can focus on reducing the number of items, or on reducing the adverse effects of the length of the PEDI. The use of a computer while interviewing can serve both. Because the items in the PEDI are ordered in increasing difficulty within subjects, the computer could determine which questions have to be asked for. Furthermore, a computer scan could warn the interviewer, for instance when a child has mastered a difficult skill but not an easier one.

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Nederlandse samenvatting

(summary in Dutch)

De kinderrevalidatie is een snel veranderende discipline. Nieuwe inzichten hebben ervoor gezorgd dat de nadruk in interventies bij kinderen met beperkingen in het dagelijks leven verschoven is van het kind naar zijn directe omgeving. De omgeving (ouders, broers en zussen, maar ook de fysieke omgeving) vormt immers de context waarin het kind opgroeit, waarvan het kind in meer of mindere mate afhankelijk is, en is als zodanig ook van belang bij interventies. Ook staan in de behandeling niet langer de beperkingen van het kind centraal, maar de functionaliteit.

Om deze nieuwe inzichten in de praktijk te kunnen gebruiken moeten instrumenten voor diagnostiek en evaluatie ontwikkeld worden die hierop aansluiten. Soms zijn dergelijke instrumenten al ontwikkeld in een ander land: onderzoekers moeten dan besluiten of ze deze instrumenten aanpassen voor gebruik in hun eigen land, of zelf nieuwe instrumenten ontwerpen. Een eenvoudige vertaling van de inhoud van de instrumenten is veelal onvoldoende, vooral als het gaat om aspecten van menselijk gedrag die veelal deels cultureel bepaald zijn. In een dergelijk geval wordt een cross-culturele adaptatie aanbevolen. Dit proefschrift beschrijft de ontwikkeling van de Nederlandse versie van de Pediatric Evaluation of Disability Inventory (PEDI) en het onderzoek dat daar vervolgens mee gedaan is om de bruikbaarheid vast te stellen.
Allereerst wordt de cross-culturele adaptatie beschreven (hoofdstuk 2) en wordt de betrouwbaarheid en validiteit van de PEDI-NL besproken (hoofdstuk 3 en 4). Vervolgens worden de bepaling van normwaarden beschreven die gebaseerd zijn op een grote steekproef van Nederlandse kinderen (hoofdstuk 5). Als laatste is de Nederlandse versie van de PEDI vergeleken met de oorspronkelijke Amerikaanse versie om de mate van equivalentie na te gaan (hoofdstuk 6).

DE PEDI, origineel ontworpen voor de Noord-Amerikaanse populatie, wordt gebruikt om de functionele status vast te stellen van kinderen in de leeftijd van 6 maanden tot 7½ jaar. Functionele status is de mate waarin een kind de gewone dagelijkse activiteiten onafhankelijk van zijn of haar ouders uit kan voeren. Dagelijkse activiteiten zijn bijvoorbeeld eten, drinken, persoonlijke verzorging, aan- en uitkleden, in en uit bed gaan, buiten lopen, in en uit de auto gaan, communicatie, spelen met andere kinderen, helpen in het huishouden en persoonlijke veiligheid. De onafhankelijkheid in het uitvoeren van dagelijkse activiteiten hangt enerzijds af van de vaardigheden die een kind bezit: als een kind onvoldoende vaardig is, is uitvoering onafhankelijk van de ouders niet mogelijk en heeft het kind hun hulp nodig. Anderzijds hangt een onafhankelijke uitvoering samen met de fysieke en sociale omgeving waarin het kind leeft. Deze omgeving kan het kind de mogelijkheden bieden om zich de vaardigheden te verwerven die nodig zijn voor een onafhankelijke uitvoering en het kind ook in staat stellen om, als het beschikt over de benodigde vaardigheden, de activiteiten onafhankelijk uit te voeren. De vaardigheden zijn in de PEDI vertegenwoordigd in de Functionele Vaardighedenschaal (FVS); deze schaal

bevat meer dan 200 items die 1 (kind beheerst de vaardigheid in de meeste situaties) of 0 (kind beheerst de vaardigheid niet) gescoord kunnen worden. De uiteindelijke uitvoering wordt gemeten met de Verzorgersassistentieschaal (VAS): hierin wordt de hoeveelheid hulp gescoord die de ouder in het normale dagelijks leven geeft op een ordinale zespuntsschaal lopend van score 0 waarbij de ouder alle activiteiten uitvoert tot score 5 waar het kind zelf alle activiteiten uitvoert zonder hulp van zijn ouders. Daarnaast wordt de Aanpassingenschaal (AS) gebruikt waarmee de soort en de uitgebreidheid van dagelijks gebruikte hulpmiddelen en aanpassingen geteld worden. De activiteiten zijn onderverdeeld in drie domeinen: Zelfverzorging, Ambulantie en Sociaal functioneren. De PEDI kan worden afgenomen als gestructureerd interview met een ouder of verzorger van het kind.

De PEDI is vertaald en aangepast voor gebruik in Nederland. Tijdens de adaptatie zijn acht items toegevoegd aan de Functionele Vaardighedenschaal die gezien worden als essentiële functionele activiteiten in Nederland. Het gaat hierbij bijvoorbeeld om eten met mes en vork en fietsen. Verder zijn sommige bestaande items aangepast aan Nederlandse gewoonten, zoals het gebruik van de douche in plaats van een bad, en zijn methodologische verbeteringen aangebracht. De PEDI-NL is vervolgens voorgelegd aan 31 deskundigen om de inhoudsvaliditeit te beoordelen: zij waren van mening dat de PEDI-NL gebruikt kan worden om de functionele status bij Nederlandse kinderen vast te stellen, om daarmee onderscheid te maken tussen kinderen met en kinderen zonder beperkingen en veranderingen in functionele status die zich in de loop van de tijd voordoen na te gaan. Zowel de betrouwbaarheid als de interne consistentie zijn onderzocht bij kleine steekproeven kinderen met en zonder beperkingen en in orde bevonden. Verder is aangetoond dat de PEDI-NL onderscheid kan maken tussen kinderen met en kinderen zonder beperkingen: de PEDI-NL-scores zijn gebruikt om te voorspellen of een kind een functionele beperking had, en in meer dan 90% van de gevallen was die voorspelling correct.

Om Nederlandse normwaarden vast te stellen is een toevallige steekproef getrokken uit alle kinderen in de leeftijd tussen 6 maanden en 7½ jaar die in de provincie Utrecht wonen. De PEDI-NL is afgenomen bij ouders van 1849 kinderen om zo vast te stellen over welke functionele vaardigheden kinderen zonder beperkingen op een bepaalde leeftijd beschikken, en om vast te stellen hoe onafhankelijk de kinderen op een bepaalde leeftijd de dagelijkse activiteiten uitvoeren. Rasch analyses werden gebruikt bij de verwerking van al deze gegevens. Hiermee is de rangorde in moeilijkheid van de items vastgesteld. Verder zijn leeftijdsafhankelijke normwaarden bepaald en leeftijdsonafhankelijke schaalscores. Deze schaalscores geven de vaardigheid van een kind weer gebaseerd op het totaal aantal items dat een kind beheerst, de normwaarden zijn bepaald voor 14 afzonderlijke leeftijdsgroepen van elk een half jaar. De steekproef waarop deze scores gebaseerd zijn was

representatief voor Nederland voor wat betreft leeftijd en geslacht, maar kinderen van hoger opgeleide ouders waren oververtegenwoordigd in de steekproef. Kinderen van etnische minderheden, daarentegen, waren ondervertegenwoordigd. De correlaties tussen deze variabelen en de PEDI-NL-scores waren echter laag; dit geeft aan dat de PEDI-scores de daaruit voortvloeiende normwaarden slechts in geringe mate hebben beïnvloed.

Ter afronding is de Nederlandse versie van de PEDI vergeleken met de oorspronkelijke Amerikaanse versie. Het concept dat gemeten wordt is in beide versies equivalent: de structuur van de PEDI-NL is hetzelfde als de structuur van de originele versie, en ook de rangordening van de items van makkelijk naar moeilijk laat vele overeenkomsten zien. De kleine verschillen in rangordening die werden gevonden duiden waarschijnlijk op culturele verschillen tussen Nederland en Amerika.

Instrumenten waarmee aspecten die een belangrijke rol spelen in de kinderrevalidatie gemeten kunnen worden zijn noodzakelijk in de ondersteuning en evaluatie van zowel interventies als onderzoek. Door het cross-cultureel aanpassen van bestaande instrumenten die oorspronkelijk ontwikkeld zijn voor gebruik in andere landen, kan tijd en geld bespaard worden, maar zijn de instrumenten toch specifiek voor onze samenleving. De Nederlandse kinderrevalidatie heeft met de PEDI-NL een betrouwbaar en valide instrument in handen voor het bepalen van de functionele status van kinderen met beperkingen in het dagelijks leven, een instrument dat zowel in inhoud als in normwaarden is toegespitst op gebruik in Nederland. Dit is dan ook een belangrijke mijlpaal in de ontwikkeling van deze discipline.

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Een jaar geleden was dit proefschrift al bijna af, maar er ontbrak nog iets aan. Inmiddels is duidelijk geworden wat er aan ontbrak: *ervaring* met beperkingen in het dagelijks leven. Na het breken van mijn enkel eind mei was ook voor mij in één klap duidelijk wat het betekent om afhankelijk te zijn van anderen in dagelijkse taken. Zelfredzaamheid kreeg opeens een andere dimensie: in mijn beleving behoorde het hebben van beperkingen in het dagelijks leven tot de dingen die in theorie iedereen kunnen gebeuren, maar in de praktijk alleen anderen overkomen. En opeens was dat ook voor mij een keiharde realiteit. Gelukkig is uiteindelijk alles op zijn pootjes terecht gekomen...

Dit proefschrift was er niet geweest zonder de steun van vele mensen. Mijn promotoren, professor dr Harm ’t Hart, professor dr Adri Vermeer en professor dr Paul Helders hebben mij met al hun kennis, ervaring en contacten bijgestaan bij de opzet, de financiering en de uitvoering van het onderzoek.
Harm was de rots in de branding en bleef, wat er ook gebeurde, kalm en vol vertrouwen dat het goed zou komen. Ook de oprechte interesse in het welbevinden van mij en mijn gezin zorgde voor een goede sfeer, en onze gezamenlijke tweeling-ervaring was daar een mooi onderdeel van.
Adri is samen met Paul de initiatiefnemer geweest voor het onderzoek, maar gedwongen door de omstandigheden destijds heb ik het onderzoek voornamelijk onder verantwoordelijkheid van Harm uitgevoerd. Dat betekende vooral dat ik fysiek op een andere plaats in het gebouw mijn werk deed, in het begin zelfs in een ander gebouw, waardoor hij niet iedere dag mij en mijn werk in de gaten kon houden. En mijn eigenschap te wachten met vragen om hulp tot ik er zelf echt niet meer uit kwam maakt het er voor mijn begeleiders niet makkelijker op. Mede door de praktische instelling van Adri waren oplossingen toch vaak snel gevonden.
Het zal ergens aan het begin van het proces geweest zijn dat Paul tegen mij en Jan Custers zei ‘vanaf nu staat er dus nog maar één ding in jullie agenda, promoveren’. Paul heeft lange tijd getracht, soms subtiel maar meestal zonder omhaal, dit na te streven, maar heeft uiteindelijk geaccepteerd dan ik ook andere besognes had. Vooral in de laatste fase was Paul een zeer betrokken en doortastende promotor. Harm, Adri en Paul, heel hartelijk dank voor jullie begeleiding en het vertrouwen dat ik kreeg om dit project voor een groot deel naar mijn eigen inzichten uit te voeren.

Ik ben in staat gesteld dit onderzoek uit te voeren binnen mijn aanstelling als docent bij de capaciteitsgroep Methodenleer en Statistiek. De capgroep heeft zich al die tijd actief ingezet voor het creeren van mogelijkheden om onderwijstijd tijdelijk om te kunnen zetten in onderzoekstijd en mij de noodzakelijke faciliteiten te bieden. Met name Maureen Postma wil ik heel hartelijk danken voor het vele werk en de initiatieven die ze in dit kader heeft ontplooid. Van de promotoren was Adri Vermeer ook degene met financiën in zijn portefeuille en hij heeft meer dan eens aangegeven dat instrumentontwikkeling belangrijk maar ook kostbaar onderzoek is, waarvoor

fondsen niet vaak bereid zijn om dat te financieren omdat de resultaten niet direct zichtbaar de kwaliteit van leven van kinderen met beperkingen verbeteren. Hij heeft Stichting Nationaal Fonds Het Gehandicapte Kind echter kunnen overtuigen van het belang van dit onderzoek en dit fonds heeft een subsidie toegekend. Daarnaast heeft ZorgOnderzoek Nederland (Zon Mw) ons onderzoek gesubisidieerd in het kader van het PERRIN-onderzoek.

Samen met dr Jan Custers, kinderfysiotherapeut, ben ik dit onderzoek begonnen. Het feit dat we een zeer verschillende achtergrond hadden maakte dat we vanaf het begin pittige discussies gevoerd hebben over de uitvoering van het gehele onderzoek. Ik heb ervan geleerd dat er andere prioriteiten kunnen zijn dan het uitvoeren van een in alle opzichten perfect onderzoek. Publiceren is één van die dingen omdat daarmee onze inspanningen voor een groot publiek toegankelijk gemaakt worden. Met trots kunnen we dan ook binnenkort de handleiding van de PEDI-NL presenteren die bij Harcourt wordt uitgegeven. Jan, bedankt voor de samenwerking en ik hoop dat we ook in de toekomst ons nog regelmatig samen zullen buigen over dingen die de PEDI-NL betreffen.

Voor het onderzoek was de medewerking van ouders van kinderen met en zonder beperkingen absoluut noodzakelijk. Met als belangrijk motief het vooruithelpen van de wetenschap om te komen tot een instrument dat in de praktijk toegepast zou gaan worden hebben zij hun medewerking verleend. Ik dank ze hiervoor heel hartelijk. Een groot woord van dank wil ik ook uitspreken naar de medewerkers van de Provinciale Entadministratie Utrecht/Noord-Holland, die voor mij de steekproef getrokken hebben uit alle Utrechtse kinderen in de leeftijd van een half tot zeven-en-een-half jaar. Hans van der Voorn en zijn medewerkers hebben vele inspanningen hiervoor moeten doen, en ik ben hen dankbaar voor de prettige samenwerking. Ik dank ook de 49 interviewers die de ruim 1800 interviews afgenomen hebben in het kader van het normeringsonderzoek voor al het werk dat ze voor mij gedaan hebben, en Roland Holdinga voor al zijn werk bij het maken van folders, de reproductie en het uittypen van adreslijsten.

Heel veel lieve vrienden, collega's en familieleden hebben een bijdrage geleverd aan de totstandkoming van dit proefschrift. Door jullie vaak morele maar soms ook praktische ondersteuning kan ik nu eindelijk mijn proefschrift verdedigen. In moeilijke tijden is het soms lastig om het hoofd boven water te houden, en juist dan blijkt hoeveel jullie allemaal om mij geven. Het is een cliché, maar het is onmogelijk om iedereen bij naam te noemen. Zonder iemand tekort te willen doen wil ik een paar mensen expliciet bedanken. Allereerst Wim Kremers en Cora Maas, méér dan collega's, vandaar dat ik hen gevraagd heb om mijn paranimfen te zijn. Wim, bedankt dat je altijd hebt klaar gestaan om praktische dingen op het gebied van onderwijs van mij over te nemen en mij daarmee in de gelegenheid gesteld enige

voortgang in het geheel te houden. Ook je morele steun was geweldig, want al die tijd dat wij een kamer deelden heb je alle ups en downs mee moeten maken! Cora, in de loop van de jaren ben je steeds doortastender geworden in je opmerkingen en je adviezen en daarmee heb je mij vaak door lastige periodes heen gesleept. Je 'kom maar, dat doe ik wel even' was vaak heel motiverend om ook zelf weer de nodige stappen te zetten. En, de kinderen vragen wanneer Cora weer komt...! Voor beiden geldt: wat jullie voor mij gedaan hebben de afgelopen jaren is veel en veel meer dan je van een collega kunt verwachten, echt geweldig.
Met andere collega's, vooral de vrouwelijke die de afgelopen jaren ook moeder geworden zijn, deel ik ervaringen die betrekking hebben op de combinatie van het ouderschap en werk. Niet iedereen is uiteraard even geïnteresseerd in het leven van een werkende moeder, en het is ook niet zo dat we het nergens anders over kunnen hebben, maar soms moet je even kunnen zeuren dat je slecht geslapen hebt vannacht... Dank jullie wel!
Dorine, kamergenoot en mede-promovendus. De onderwerpen van onze dissertaties hebben geen enkel raakvlak, maar toch hadden we vergelijkbare ervaringen vaak vergelijkbaar. Mijn proefschrift is af, en in 2007 heb ik al een plekje gereserveerd voor jouw verdediging. Ik zal proberen je daarbij te ondersteunen zoals jij de afgelopen jaren bij mij hebt gedaan, waarvoor heel veel dank!
Lieve Mieneke, hoe anders had alles kunnen lopen als wij samen dit project uitgevoerd hadden? In onze studie hebben we perfect samengewerkt, we deelden het beoefenen van het Acrobatisch Rock 'n' Roll dansen, inmiddels hebben we beiden kinderen die opvallende gelijkenissen vertonen en nu mijn project afgerond is begin jij aan een nieuw project. Dank voor de gezellige wekelijkse telefoon-gesprekken over de dingen des levens waar onze mannen niets van begrijpen, en als ik in de komende tijd iets voor jou kan doen, graag!

Papa en Mama, van dank willen jullie vast niets weten, want voor jullie is het bijna een tweede natuur geworden om ons te helpen waar nodig, maar als ik alles wat jullie voor ons gedaan hebben de afgelopen jaren zelf had moeten doen, dan stond ik hier nu niet. Veel praktische hulp, maar ook jullie steun en adviezen zijn hiervoor essentieel geweest. Dus, dank jullie wel! Hetzelfde geldt eigenlijk voor zus Kim, broer Huub en de rest van mijn (schoon-)familie: ook jullie ondersteuning is erg belangrijk geweest de afgelopen jaren. Ik hoop dat we nog lang met en van elkaar kunnen genieten en vanaf nu vooral meer *leuke* dingen samen kunnen doen. Als laatste in dit familie-rijtje wil ik de hele familie Goudriaan noemen: Mieke, Willem, Jeltje, Oda, Neeltje en hun partners. Al jaren is onze band heel bijzonder en vertonen onze levens ondanks een leeftijdsverschil van een halve generatie veel overeenkomsten. Ik koester jullie lieve kaarten, e-mailtjes, bezoekjes,logeerpartijtjes en praktische lay-outtips, bedankt!

Frank, Mirjam, Karin en Lieke, onze vier (b-)engeltjes. Jullie komst heeft niet alleen mijn leven maar ook mijn onderzoek verrijkt en verdiept, het heeft me bij de ontwikkeling van de PEDI-NL meer inzicht gegeven in de andere kant, de kant van de ouders die de vragen moeten beantwoorden. Jullie hebben me steeds laten inzien dat er, sorry Paul, eigenlijk maar één ding echt belangrijk is in het leven, mijn gezin. Ik zou niet zonder mijn werk kunnen, maar in geval van nood moet alles wijken voor jullie. Alle vier hebben jullie zo jullie eigen invloed gehad de afgelopen jaren: hoewel ik geprobeerd heb zo veel mogelijk werk en gezin te scheiden kregen jullie uiteraard de ups en downs toch mee. En dan krijg je terug wat je erin stopt: onvoorwaardelijke liefde, maar ook je eigen opmerkingen…. Frank, grote behulpzame zoon van inmiddels 7 jaar, je kunt af en toe met een perfect gevoel voor timing zeggen ‘Ja, Mama, zo is het leven…..!!’. Dank je wel voor je tekening van de dinosaurus op krukken! Mirjam, grote dochter van 5, je geeft me dikke knuffels en deelt uit liefde alles wat je hebt met me. En Karin en Lieke, net twee jaar nu, jullie zorgen er wel voor dat ik als ik bij jullie ben niet aan het werk kán denken: voor ik het weet gaat de één links en de ander rechts en staan jullie midden op straat, klimmen de trap op of gooien jullie alle puzzels op de grond! En maar giebelen! Hoe heerlijk ongecompliceerd is het leven van een tweejarige…

Rudy, dit proefschrift was waarschijnlijk de zwaarste bevalling, voor ons allebei. Het valt niet mee om je leven te delen met een vrouw die de zorg voor je grote gezin combineert met een baan die bij tijd en wijle veel tijd en energie verslindt en in beide rollen ook nog een zeker perfectionisme nastreeft. Niet zelden kwam jij op het laatste plan de afgelopen jaren, maar je hebt nooit geklaagd. Alleen aan het tijdstip waarop je naar bed ging viel af te leiden dat je het er soms moeilijk mee had. Nu de meisjes ook wat minder afhankelijk van me zijn moeten we maar weer eens samen op stap gaan. Ik hou van je!

Ik wil dit proefschrift graag opdragen aan degenen die letterlijk en figuurlijk aan de wieg van mijn wetenschappelijke carrière hebben gestaan: Oma Severijnen en Opa Bezemer. Allen die hen gekend hebben zullen zich hun bijzondere wetenschappelijke interesse herinneren.

Curriculum vitae

Jeltje Wassenberg-Severijnen was born in Aarle-Rixtel, the Netherlands, on April 9, 1967. In 1986, she finished secondary school (VWO-β) at the Carolus Borromeus College in Helmond. She studied psychology at Utrecht University from 1986 until 1991, and finished her study with a research project on corporate fitness.

After her graduation she assisted several researchers in data collection and data analysis. Since 1991, she also teaches statistics to social scientist students. In 1997 she started this study on the Dutch version of the Pediatric Rehabilitation of Disability Inventory (PEDI). In the autumn of 2005, the manual of the Dutch version will be published by Harcourt Test Publishers.

Jeltje Wassenberg-Severijnen is married to Rudy Wassenberg, and has four children: Frank (born in 1998), Mirjam (born in 2000) and Karin en Lieke (born in 2003).