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Reliability of the modified Paediatric Evaluation of Disability Inventory, Dutch version (PEDI-NL) for children with cerebral palsy and cerebral visual impairment

M. Salavati^{a,b,*}, A. Waninge^{a,b}, E.A.A. Rameckers^{c,d,e}, A.C.E. de Blécourt^f,
W.P. Krijnen^b, B. Steenbergen^{g,h}, C.P. van der Schans^{b,f}

^a Royal Dutch Visio, Centre of Expertise for Blind and Partially Sighted People, The Netherlands

^b Hanze University of Applied Sciences Groningen, Research and Innovation Group in Health Care and in Nursing, Groningen, The Netherlands

^c Maastricht University, Department of Rehabilitation Medicine, School for Public Health and Primary Care (CAPHRI), Maastricht, The Netherlands

^d Adelante Center of Expertise in Rehabilitation and Audiology, Valkenburg and Hoensbroek, The Netherlands

^e AVANSplus, University for Professionals for Paediatric Physical Therapy, Breda, The Netherlands

^f University Medical Center Groningen, Department of Rehabilitation Medicine, Groningen, The Netherlands

^g Australian Catholic University, School of Psychology, Melbourne, Australia

^h Radboud University Nijmegen, Behavioural Science Institute, Nijmegen, The Netherlands

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ABSTRACT

Purpose: The aims of this study were to adapt the Paediatric Evaluation of Disability Inventory, Dutch version (PEDI-NL) for children with cerebral visual impairment (CVI) and cerebral palsy (CP) and determine test–retest and inter-responder reliability.

Method: The Delphi method was used to gain consensus among twenty-one health experts familiar with CVI. Test–retest and inter-responder reliability were assessed for parents and caregivers of 75 children (aged 50–144 months) with CP and CVI. The percentage identical scores of item scores were computed, as well as the interclass coefficients (ICC) and Cronbach's alphas of scale scores over the domains self-care, mobility, and social function.

Results: All experts agreed on the adaptation of the PEDI-NL for children with CVI. On item score, for the Functional Skills scale, mean percentage identical scores variations for test–retest reliability were 73–79 with Caregiver Assistance scale 73–81, and for inter-responder reliability 21–76 with Caregiver Assistance scale 40–43. For all scales over all domains ICCs exceeded 0.87. For the domains self-care, mobility, and social function, the Functional Skills scale and the Caregiver Assistance scale have Cronbach's alpha above 0.88.

Conclusion: The adapted PEDI-NL for children with CP and CVI is reliable and comparable to the original PEDI-NL.

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* Corresponding author at: Royal Visio, Center of Expertise for Blind and Partially Sighted People, Rijksweg 286, 9752 CL Haren, The Netherlands. Tel.: +31 652679733.

E-mail address: MasoudSalavati@visio.org (M. Salavati).

1. Introduction

Cerebral palsy (CP) describes a group of permanent disorders of movement and posture development, causing activity limitation; they are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. Gross motor function of children with CP is classified using the Gross Motor Function Classification System (GMFCS) into five different severity levels, where level 1 indicates the least and level 5 the most functional limitation (Dutch Institute of Rehabilitation Paediatricians, 2007; Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007). Motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour; by epilepsy; and by secondary musculoskeletal problems (Dutch Institute of Rehabilitation Paediatricians, 2007; Rosenbaum et al., 2007).

In general, children with visual impairments have more difficulty to express themselves, they are usually delayed in language skills, appear to be at a disadvantage when performing reading tasks, and learning to write can also be difficult compared to children without visual impairment. Furthermore, developmental milestones that normally require vision e.g. reaching and walking are often delayed in children with visual impairments (Good, Jan, Burden, Skoczenski, & Candy, 2001).

The spectrum of visual impairments in children with CP is extremely broad and includes both ocular visual impairment (OVI), such as strabismus, reduced visual acuity, ocular nystagmus, refraction disorders, and retinopathies, and cerebral visual impairment (CVI), which is a problem of central origin. CVI is observed in approximately 30% of children diagnosed with various forms of CP (Da Costa, Salmao, Berezovsky, De Haro, & Ventura, 2004; Dutton & Jacobson, 2001; Ghasia, Burnstroom, Gordon, & Tychsen, 2008; Schenk-Rootlieb, Van Nieuwenhuizen, Van der Graaf, Wittebol-Post, & Willemse, 1993a; Schenk-Rootlieb, Van Nieuwenhuizen, Schiemanck, Van der Graaf, & Willemse, 1993b; Schenk-Rootlieb, Van Nieuwenhuizen, Van Waes, & Van der Graaf, 1994; Stiers et al., 2002). CVI can be defined as deficient visual function, as a sequel of damage or malformation of the retrogeniculate visual pathways (optic radiations, occipital cortex and visual association areas); in the absence of damage of the anterior visual pathways or any major ocular disease. Also, CVI is diagnosed by exclusion of OVI. CVI is a prominent sequel to premature birth, particularly when prematurity is extreme (Dutton & Jacobson, 2001). The focus of this study will be on CVI because the need of children with OVI is different to those with CVI (Da Costa et al., 2004; Dutton & Jacobson, 2001; Ghasia et al., 2008; Schenk-Rootlieb et al., 1993a, 1993b, 1994; Stiers et al., 2002).

The role of visual perception during motor action and development is very important, because children with CP show increased visual monitoring during motor activities (walking, daily-life activities and play), and this emphasises the role of visual perception during motor action (Varrel, Bekkering, & Steenbergen, 2008). Considerable focus has been directed towards the detection and treatment of prematurity-caused retinopathy, but there tends to be less of a focus on CVI, which can consequently be overlooked. Dutton and Jacobson (2001), focused primarily on profound visual impairment in children experiencing CVI. CVI ranges in severity from blindness to relatively minor impairments of visual perception. Perceptual visual dysfunction and disorders of visual attention, often with only minimally reduced or normal visual acuities, are increasingly recognised as forms of CVI (Dutton & Jacobson, 2001; Fazzi et al., 2012; Dutton, 2013). It is stated that CVI has an impact on all aspects of child's development, and children with CP and CVI develop more slowly in the area of Self-care, Mobility and Social Function than children with CP and no CVI. However, children with CVI exhibit slow, inefficient, and highly variable visual performance during daily-life activities (Da Costa et al., 2004; Dutton & Jacobson, 2001; Dutton, 2013; Ghasia et al., 2008; Good et al., 2001; Salavati, Rameckers, Steenbergen, & Schans van der, 2014; Schenk-Rootlieb et al., 1993a). It is important to evaluate daily-life activities for Self-care, Mobility and Social Function in children with CVI by a reliable and valid test. This is the subject of our study.

The PEDI-NL (Wassenberg-Severijnen & Custers, 2005; Wassenberg-Severijnen, Custers, Hox, Vermeer, & Helders, 2003; Custers et al., 2002) is a questionnaire that evaluates the daily skills of children aged 6 months to about 7.5 years. It measures both capability (what the child can do) and performance (what the child actually does) of daily routine childhood activities in the Self-care, Mobility and Social Function domains, using a structured interview with the parents or caregivers (Wassenberg-Severijnen & Custers, 2005; Wassenberg-Severijnen et al., 2003; Custers et al., 2002). A child's capability can be measured utilising the PEDI-NL's three Functional Skills scales, performance using its three Caregiver Assistance scales and Modification scales. Reliability of the PEDI-NL in children with CP without CVI is sufficient (Wassenberg-Severijnen et al., 2003), yet the validity and reliability study assessment did not include children with visual impairment (Wassenberg-Severijnen et al., 2003). Professionals working with children with CVI and CP at Royal Dutch Visio and Bartiméus, centres of expertise for blind and partially sighted people in The Netherlands, experienced that the PEDI-NL does not account for the presence of CVI and might not be appropriate for children with CVI due to their difficulties at different levels of functioning. Also, as a consequence of CVI a child might not be able to show his/her full capacity in the domains of Self-care, Mobility and Social Function during the standardised assessment of a developmental test (Salavati et al., 2014; Wassenberg-Severijnen et al., 2003; Haley, Coster, Ludlow, Haltiwanger, & Andrellos, 1992; Visser, Ruiter, Meulen van der, Ruijsenaars, & Timmerman, 2014). In line with this, there are no reliable and valid instruments available to measure these domains in children with CP and CVI (Custers et al., 2002). Considering the fact that a high number of children with CP also has CVI, it is very important for paediatric physical therapists and occupational therapists to have at their disposal an instrument that is adapted for children with CVI, because the original PEDI-NL renders inaccurate performance outcome results and negative impacts for treatment. In this study we developed an adapted version of the PEDI-NL and determine its test–retest reliability and inter-respondent reliability for children with CVI and CP.

2. Methods

The study was carried out in two phases. First, the PEDI-NL (Table 1) was adapted for children with CVI. Second, the psychometric properties of the adapted PEDI-NL were examined in children with CP and CVI.

Table 1 gives an overview of topics in the PEDI-NL. Both the capability of the child (Functional Skills scale, 201 items) and the amount of help he/she gets from his/her parents (Caregiver Assistance scale, 20 items) as well as the equipment used (Modifications scale, 20 items) in daily tasks are measured by a structured interview with parent(s) and caregivers. Functional Skills are determined in three domains: Self-care, Mobility and Social Function.

Items in the Functional Skills scale are dichotomous and are scored as either 'capable' or 'not capable'. Summed scores can be computed in every domain and transformed to standardised scores. Both the Caregiver Assistance Scale and the Modifications Scale are ordinal scales, ranging from 'totally dependent' to 'totally independent' (Wassenberg-Severijnen et al., 2003). The Modifications Scale measuring the equipment used is an ordinal scale, and consists of "no modifications", "child-oriented modifications", "specialised rehabilitation equipment", and "extensive modifications" (Wassenberg-Severijnen et al., 2003).

2.1. Phase 1

2.1.1. Adaptation

The Delphi method was used to gain consensus among a panel of experts. It is applied in a series of sequential questionnaires or 'rounds', interspersed by controlled feedback, in order to seek for the most reliable consensus of opinion of a group of experts (Powell, 2003).

Table 1
Content of the PEDI-NL (Wassenberg-Severijnen, Custers, Hox, Vermeer, & Helders, 2003).

Domains	Functional Skills scale/subscales	Number of items	Caregiver Assistance scale Modifications scale
Self-care	Types of food textures	4	Eating
	Use of utensils	6	
	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	5	Bed mobility/transfers
	Tub transfers	5	Tub transfers
	Indoor locomotion methods	3	Indoor locomotion
	Indoor locomotion-distance/speed	5	
	Indoor locomotion-pull/carriers objects	5	
	Outdoor locomotion methods	3	Outdoor locomotion
	Outdoor locomotion-distance/speed	5	
	Outdoor surfaces	5	
	Up stairs	5	Stairs
	Down stairs	5	
Social Function	Comprehension of word meanings	5	
	Comprehension of sentence complexity	5	
	Functional use of communication	5	
	Complexity of expressive communication	5	
	Problem resolution	5	
	Social interactive play (adults)	5	
	Peer interactions (child of similar age)	6	
	Play with objects	5	
	Self-information	5	
	Time orientation	5	
	Play with objects	5	
	Self-protection	5	
	Community function	5	

Firstly, we identified relevant disciplines and their skills, giving those experts the opportunity to participate by e-mail in the study of adaptation of PEDI-NL. We invited experts with different backgrounds to the study of adaptation of PEDI-NL if they had experience with children who have CVI. All of them worked at Royal Dutch Visio and Bartiméus, centres of expertise for blind and partially sighted people in the Netherlands. Secondly, we explained to the expert the purpose of this study and the required procedures. All of the invited experts confirmed their desire to participate. The experts were asked for their age, profession, working experience and familiarity with the PEDI-NL.

2.1.2. Data collection for adaptation

The health experts familiar with CVI participated in the adaptation process by studying the PEDI-NL, and when required adapted the instruction part of the content for children with CVI. Specific feedback information could be written about any of the items. E-mail was used to process and resubmit all experts' comments in three rounds. The predetermined goal was to reach a consensus of 65% among the experts after the first round, 75% second round and 85% third round for agreement with the content of the adapted version of PEDI-NL. Also, the experts were asked to explain and justify their comments on each question and instruction, without changing the original questions and instructions. No items were eliminated from the original PEDI-NL during the adaptation process.

2.1.3. First round

All experts were invited to study the instruction part of the PEDI-NL, then gave comments individually from their viewpoint on each question and original instruction. In accordance with other studies (Ghasia et al., 2008; Dutton & Jacobson, 2001; Dutton, 2013; Steendam, 2007) on CVI, the experts were specifically asked:

Which verbal support/instruction or manual support needs to be added to the instruction of the PEDI-NL to make it suitable it for children with CVI? At the equipment level: what kind of adjustment needs to be added to the instruction of the PEDI-NL to make it suitable it for children with CVI?

For use of manual support they were asked, as applicable, to describe the amount of manual support (e.g. duration and phase of needed manual support given) in order to help a child accomplish a particular skill. At the level of verbal support they were asked, as applicable, what especially should be said in order to help a child accomplish a particular skill. For use of materials they were asked which characteristics a material needed to have (e.g. colourful, sound-produced, high in contrast) to receive the attention of a child with CVI in order to use this specific material.

2.1.4. Second and third rounds

After receiving the experts' comments on the questions and instruction of PEDI-NL, we processed all of the suggestions in the instruction part of PEDI-NL and resubmitted this twice to the experts. We asked again the same questions as in the first round.

2.2. Phase 2

2.2.1. Participants

Children with CP and CVI were recruited from Royal Dutch Visio and allied health care practices. Inclusion criteria were presence of all types of CP and CVI, mild or moderate intellectual disability, and age at testing of the modified PEDI-NL for children with CVI between 4 and 12 years. Level of intellectual disability was reported from the children's medical files; Children with a syndrome (e.g. Down syndrome) and hearing difficulties (<30 db) were excluded. Also, children with severe or profound intellectual disability ($IQ < 60$) were excluded. The diagnosis of CP and the classification according to GMFCS level were aggregated from the children's medical files and judged by a rehabilitation specialist.

CVI is a heterogeneous diagnosis with large variability between children and it can present in many forms. The diagnosis of CVI was determined based on the results of ophthalmological and (neuro-) psychological research, and on the assessment data reported by a developmental coach specialised in working with children with visual impairments (Fig. 1). According to these, the diagnosis of CVI was determined by the following criteria: a normal or near normal eye exam performed by ophthalmologist; a history or presence of neurological problems; presence of behavioural responses to visual stimuli which are unique to CVI. This results in strong colour preference, need for movement to elicit or sustain visual attention, visual latency-delayed responses in looking at objects, visual field preferences, difficulties with visual complexity, light-gazing and non purposeful gaze, difficulty with distance viewing, absent or atypical visual reflexes, difficulty with visual novelty, and absence of visually guided reach. Also, Children with (corrected) vision < 0.3 and/or field of vision $\leq 30^\circ$ were excluded. In our study, all children with CVI were included.

This study was approved by the Medical Ethical Committee (METC-2013.104) of University Medical Center Groningen (UMCG), the Netherlands. Written informed consent was obtained from the children's parents.

2.3. Design

For test–retest reliability the same caregiver familiar to the child, was interviewed twice by a therapist, within three weeks. For inter-respondent reliability we used the data of one of the parents and the caregiver within a few days, in order to

Fig. 1. Procedure for inclusion.

prevent overload of the parents. The therapists conducted all interviews with parents and caregivers. The caregiver was a person with knowledge and skills on how take care of the child e.g. at school and was familiar with the child.

The percentage identical scores of item scores were computed, and interclass coefficients (ICC) and Cronbach's alphas for domain Self-care, Mobility and Social Function were calculated.

2.4. Data collection

We collected data on gender as well as prevalence of epilepsy and speech/language development according to the International Classification of Functioning, Disability and Health for Children and Youth (Dutch Translation, 2008) to account for the possible effect on Self-care, Mobility, and Social Function. At the level of speech/language development, the collected data were: d3100 = reacts to human voice; d3101 = understands simple spoken messages; d3102 = understands complex spoken messages; d330 = speaks; d331 = babbles; d3350 = uses body language and d3351 = uses signs symbols (Table 3). The data of children were registered according to GMFCS level and type of CP (unilateral or bilateral), level of intellectual disability, and age at which the PEDI-NL were administered.

2.5. Statistical analyses

The data were analysed using the Statistical Package for Social Sciences (SPSS), v.22 software. Inter-respondent reliability and test-retest reliability were established using the partial (item) and total (scale) scores of PEDI-NL-CVI from children with CP and CVI. To calculate reliability of the modified PEDI-NL for children with CVI, we used the proportion of identical answers on every item. Also, intraclass correlation coefficients (ICC, two-way random, absolute agreement, single measure) and their confidence intervals of test-retest reliability and inter-respondent reliability for each domain were calculated. The two-way random variant of ICC for single measurements was chosen to measure degree of absolute agreement because the children as well as the observers were a random factor in the design (McGraw & Wong, 1996; Lexell & Downham, 2005). *P*-values below 0.05 were considered statistically significant. To test for systematic bias, the mean of the differences and the standard deviation of differences were calculated by the paired *t*-test. Limits of agreement (LOA) for inter-respondent reliability and test-retest reliability of the Functional Skills (FS) and Caregiver Assistance (CA) scales (domains Self-care, Mobility, Social Function) were calculated.

Internal consistency of each domain in the Functional Skills scale and the Caregiver Assistance scale was assessed by Cronbach's alpha based on the caregiver measurement. The value of Cronbach's alpha (Cronbach, 1951) was interpreted as: poor < 0.5, moderate 0.5–0.75, good 0.75–0.9, excellent > 0.9. Test-retest reliability for the Functional Skills and Caregiver Assistance scales was examined using intraclass correlation coefficients (ICCs). The ICC was used to analyse the agreement between the interviews from each of two domains. The ICC value was interpreted as follows: poor < 0.5, moderate 0.5–0.75, good 0.75–0.9, excellent > 0.9.

3. Results

3.1. Phase 1

3.1.1. Adaptation

Twenty-one health experts familiar with CVI participated in the adaptation process of the PEDI-NL; sixteen of them (male:female = 2:14) were paediatric physical therapists, two (male:female = 0:2) occupational therapists, one female speech and language therapist, and two (male:female = 1:1) behavioural scientists. Mean (SD) age of the experts was 50 (10) years and their mean years (SD) of experience with children with CVI was 18 (8). Nineteen of them were familiar with the PEDI-NL.

3.1.2. Delphi first round

Sixty-five percent of the experts agreed on the instruction part of PEDI-NL. With respect to the original instruction, most adaptations were at the Functional Skills scale and Caregiver Assistance scales, on domain Self-care and Mobility. Also, the largest agreement amongst experts was encountered on domain Self-care and Mobility. For example, at the level of using 'a cup or a spoon' the child needed to know about the object in advance in order to locate it. It is thus assumed that the child with CVI receives verbal and manual support. Furthermore, during a toilet transfer the child uses the hands in order to orient itself to walk to the bathroom. Hence while the child with CVI walks to the bathroom, it is allowed to use the hands for orientation and not for support.

The least agreement was found on domain of Social Function. For 'Comprehension of sentence complexity', a child with CVI could have difficulty localising an object well by using visual information. It is therefore assumed that the child 'knows' the location of an object. The experts agreed that, depending on the visual impairment, children with CVI often have difficulty with 'using a bicycle in an unknown environment'. This involves moving in an outdoor familiar environment. Adult supervision is thus required for this activity, for safety reasons.

For the Modification scale, the experts gave some suggestions to add adapted equipment, such as coloured toothbrush or a coloured cup for children with CVI.

3.1.3. Delphi second round

Seventy-five percent of the experts agreed on the instruction part of PEDI-NL after the second round. Most comments were on domain of Social Function, where, in terms of inconsistency of visual perception, a child could have difficulty 'playing safely at home' or 'following the rules'. With regard to this item an additional explanation is given (Table 2). Generally, when a task is more complicated, the child will have more difficulty performing that particular task. For example, the child has difficulty running errands independently or finding his/her way home. If there is a lack of visual information, a child may have difficulty imitating. Hence the experts agreed to use verbal support in order to explain the content of visual information to a child with CVI.

3.1.4. Delphi third round

After receiving the experts' comments we processed the suggestions, mostly on domain of Social Function in the instruction part of PEDI-NL, and resubmitted to the experts. The experts responded, indicating 100% satisfaction with the resulting overall content of the adapted version of PEDI-NL (PEDI-NL-CVI). With respect to CVI the professionals applied specific feedback information, which is added as an appendix to the instruction of the original PEDI-NL. This appendix (Table 2) can be used for children with CVI. Considering the fact that visual perception contributes to the performance of daily-life activities, it is important to use the version of PEDI-NL-CVI for children who have CVI.

The experts agreed on content of the PEDI-NL-CVI, and considered that this version presented all the important issues in the specific domains for children with CVI. The adapted version consists of additional introductions for all domains such as Self-care, Mobility, Social Function, and modification or used adaptive equipment.

3.2. Phase 2

3.2.1. Inter-respondent reliability and test–retest reliability

Children were tested between June 2013 and April 2014. Mean time between the two interviews was 14 days (SD 3 days). Mean time between researcher interviews of parent and caregiver was 7 days (SD 2 days). We collected the data from 75 children with both CP and CVI ($n = 40$ boys and $n = 35$ girls). Table 3 shows the children's characteristics. All children with CVI were included in our study and no selection was done based on subtypes. Therefore, we assume that different subtypes are represented in our study.

Tables 4 and 5 present summed scores (mean scores and standard deviation) for each domain of the Functional Skills scale and the Caregiver Assistance scale from the test–retest and inter-respondent reliability assessments in children with CP and CVI.

For test–retest reliability, the mean percentage (SD) of identical scores for the Functional Skills scale was 73 (2.5) for the domain of Self-care, 76 (0.9) for Mobility and 79 (1.4) for Social Function, indicating moderate-to-good identical scores. The mean percentage (SD) of identical scores for the Caregiver Assistance scale was 73 (1.3) for the domain of Self-care, 81 (6.0)

Table 2
Summed changes proposed by professionals at the level of the Functional Skills scale.

Domains	Functional Skills scale/subscales	Adaptation
Self-care	Types of food textures	It is assumed that the child knows that the food will be announced verbally in advance, and will be offered at a leisurely pace
	Use of utensils	It is assumed that the child knows the position of the cutlery
	Use of drinking containers	Because children with CVI, compared to peers without CVI, have difficulty drinking without spilling, it is assumed that tasks like picking up a cup or drinking will be verbally announced
	Tooth brushing	It is assumed that the parents/caregivers will verbally announce the position of the toothbrush and toothpaste if the child doesn't know their position
	Hair brushing	It is assumed that the parents/caregivers use verbal support to help the child with this task
	Nose care	It is assumed that the parents/caregivers use verbal support to tell the child the position of the handkerchief; if necessary, they give the handkerchief to the child
	Hand washing	It is assumed that the parents/caregivers use verbal support to tell the child the position of the soap, faucets, sink, washcloth and towel
	Washing body and face	It is assumed that the parents/caregivers use both verbal and manual support to help the child find the position of the soap, faucets, sink and towel
	Pullover/front-opening garments	It is assumed that the parents/caregivers use verbal and manual support to help the child find the position of the clothes, and the clothes lie on a place that is known by the child. The child is able to scan the front and the back of the cloth, e.g. a pullover or a t-shirt
	Fasteners	It is assumed that the parents/caregivers use verbal support to help the child with these tasks
	Pants	It is assumed that the parents/caregivers use verbal and manual support to help localise the position of the clothes and to help the child dress and undress
	Shoes/Socks	It is assumed that the parents/caregivers use verbal support to help the child localise the socks and the shoes
	Toileting task	It is assumed that the parents/caregivers use verbal and manual support to help the child with these tasks
	Management of bladder	It is assumed that the parents/caregivers use verbal and manual support to help the child with these tasks
	Management of bowels	It is assumed that the parents/caregivers use verbal and manual support to help the child with these tasks
Mobility	Toilet transfers	Because the intention to move in relation to the transfer is less present in a child with CVI, it is assumed that the child uses the arms/hands to orient itself (G33). It is assumed that the parents/caregivers use verbal support to help the child with these tasks. Also, the lighting in the bathroom is adequate
	Chair/wheelchair transfers	Because of the lack of depth perception the child has an adverse influence on the transfer. It is assumed that the child is familiar with the chair, knows its location, and uses a chair with armrests. The child uses these armrests as an orientation point (see 'Caregivers Assistance' and 'Modifications Scale')
	Car transfers	The child can use its arms/hands for orientation. It is assumed that the parents/caregivers use verbal support to help the child with these tasks
	Bed mobility/transfers	Because the intention to move in relation to the transfer is less present in a child with CVI, it is assumed that the child uses the arms/hands for orientation
	Tub transfers	Because the intention to move in relation to the transfer is less present in a child with CVI, it is assumed that the child uses the arms/hands for orientation
	Indoor locomotion methods	E.g. in situations in which the child moves or is stimulated to move by visual support in the form of fluorescent toys, toys with a big contrast and/or toys that produce sound. 'Inside' means the familiar environment of the child
	Indoor locomotion-distance/speed	E.g. in situations where the child moves and follows fluorescent toys or toys that produce sound or have a big contrast, all while being verbally supported and stimulated to move. It is assumed that there are no unknown obstacles or abrupt transitions (in floor types or colours) between two rooms along the child's route
	Indoor locomotion-pull/carrier objects	It is assumed that the child must have a hand/arm free to orientate (C12), and that there are no unknown obstacles along the child's route
	Outdoor locomotion methods	Because the child has difficulty perceiving depth in relation to moving on different types of surfaces, the use of arms/hands to orientate is allowed (J46). This involves moving outside the familiar environment, and it is assumed that there are no obstacles along the child's route
	Outdoor locomotion-distance/speed	This involves moving in an outdoor familiar environment. An activity done 'without help' is still supervised by an adult for safety reasons. It is assumed that the child uses certain objects (such as a wall) to move. These objects are not used as support
	Outdoor surfaces	Because the child has difficulty perceiving depth in relation to moving across different kinds of surfaces, the use of arms/hands to orientate is allowed
	Climbing stairs	It is assumed that the child is familiar with the stairs and the height of the steps.
	Going down stairs	It is assumed that the child is familiar with the stairs and the height of the steps. In this situation the supervisor walks backwards down the stairs, verbally inviting the child to move down (depending on the demand, crawl and slide on the buttocks or walk)

Table 2 (Continued)

Domains	Functional Skills scale/subscales	Adaptation
Social Function	Comprehension of word meanings Comprehension of sentence complexity	Specific concepts such as the name of a toy that is familiar to the child Because a child with CVI cannot localise an object well, it is assumed that the child 'knows' the location of an object. For example: the child has both the cup and the plate in its hands and the researcher asks the child, 'give me your cup'. In this situation it is assumed that the child is able to give the cup to the researcher by knowing what a cup is and what a plate is. The child understands and executes the task 'the ball is under the table' because he/she has done it before and knows the route to the ball
	Functional use of communication	For all of the items listed below it is assumed that the child receives verbal support to help localise an object such as a cup
	Complexity of expressive communication	No adaptation
	Problem resolution	No adaptation
	Social interactive play (adults)	It is allowed for the child to make contact in other ways than just 'visual' contact with an adult or with a toy. It is assumed that the child receives both verbal and manual support to help find toys such as balls or building blocks (G33 and G34)
	Peer interactions (child of similar age)	The child makes not only 'visual' contact but also 'attention' contact with other children. It is assumed that the child is familiar with age-appropriate games that are played beforehand in a one-on-one situation
	Play with objects	It is assumed that in all situations the parents/caregivers use verbal support to help the child understand the game beforehand, and that the child is familiar with the rules regarding the toy
	Self-information	No adaptation
	Time orientation	No adaptation
	Self-protection	It is assumed that a child with CVI crosses the street under guidance/supervision
	Community function	This relates to both inside and outside the home and familiar surroundings. It is assumed that the child is familiar with the environment outside the house. For all items listed below it is assumed that the child receives both verbal and manual support to help with the process of familiarisation with the objects without helping him/her complete the task: for example, when the child climbs on top of the furniture it is expected to come down from it safely

Table 3

Characteristics of children with CP and CVI.

Characteristic	Children with CP and CVI
Age, months, min.–max., mean (SD)	50–144, 114 (29)
Gender, male/female (<i>n</i>)	40/35
Type of cerebral palsy	
Spastic (<i>n</i>) (%)	71 (95)
Dyskinetic (<i>n</i>) (%)	3 (4)
Ataxic (<i>n</i>) (%)	1 (1)
GMFCS I (<i>n</i>) (%)	Bilateral 17 (23), unilateral left 2 (3), unilateral right 1 (1)
GMFCS II (<i>n</i>) (%)	6 (8) bilateral
GMFCS III (<i>n</i>) (%)	10 (13) bilateral
GMFCS IV (<i>n</i>) (%)	19 (25) bilateral
GMFCS V (<i>n</i>) (%)	20 (27) bilateral
Speech/language development ICF-CY, d3100 = reacts to human voice (<i>n</i>) (%)	75 (100)
Speech/language development ICF-CY, d3101 = understands simple spoken messages (<i>n</i>) (%)	75 (100)
Speech/language development ICF-CY, d3102 = understands complex spoken messages (<i>n</i>) (%)	47 (63)
Speech/language development ICF-CY, d330 = speaks (<i>n</i>) (%)	44 (59)
Speech/language development ICF-CY, d331 = babbles (<i>n</i>) (%)	31 (41)
Speech/language development ICF-CY, d3350 = uses body language (<i>n</i>) (%)	51 (68)
Speech/language development ICF-CY, d3351 = uses signs and symbols (<i>n</i>) (%)	37 (49)
Level of intellectual disability: mild/moderate (<i>n</i>) (%)	33 (44)/42 (56)
Presence of epilepsy: yes/no (<i>n</i>) (%)	12 (16)/63 (84)
Use of epilepsy medication: yes/no (<i>n</i>) (%)	11 (15)/64 (85)
Percutaneous endoscopic gastrostomy tube feeding: yes/no (<i>n</i>) (%)	12 (16)/63 (84)

GMFCS, Gross Motor Function Classification system; *n*, numbers; ICF-CY, International Classification of Functioning, Disability and Health, Child and Youth version (Dutch translation).

Table 4

Test–retest reliability. Results of the Functional Skills (FS) and Caregiver Assistance (CA) scales. Summed scores: mean (*M*), standard deviation (*SD*), paired *t*-test, *p*-value, limits of agreement (LOA), percentage of identical scores, and ICC (CI) (*n* = 75).

PEDI-NL-CVI	1st interview <i>M</i> (<i>SD</i>)	2nd interview <i>M</i> (<i>SD</i>)	<i>t</i> -value	<i>p</i> -value	Mean of difference (LOA)	% identical scores: <i>M</i> (<i>SD</i>)	ICC (LB–UB)
FS – self-care	34 (17.5)	34 (17.3)	1.74	0.086	0.50 (±4.94)	73 (2.5)	0.99 (0.98–0.99)
FS – mobility	31 (18.5)	31 (18.6)	−1.03	0.305	−0.10 (±1.75)	76 (0.9)	1.00 (1.00–1.00)
FS – social function	37 (14.0)	37 (14.2)	−1.04	0.287	−0.10 (±2.74)	79 (1.4)	0.99 (0.99–1.00)
CA – self-care	17 (9.3)	17 (9.4)	0.43	0.665	0.06 (±2.60)	73 (1.3)	0.99 (0.98–0.99)
CA – mobility	15 (12.2)	15 (11.1)	−1.03	0.305	−0.14 (±2.48)	81 (6.0)	0.87 (0.80–0.91)
CA – social function	12 (4.7)	12 (4.9)	1.34	0.169	0.12 (±1.60)	79 (2.3)	0.88 (0.82–0.92)

ICC, intraclass correlation coefficient; LB, lower bound; UB, upper bound; CI, confidence interval.

for Mobility and 79 (2.3) for Social Function, indicating moderate-to-good identical scores. Further, all ICC values ranged from 0.87 to 1.00 for test–retest reliability (Table 4).

For test–retest reliability, the mean percentage (*SD*) of identical scores for the Modifications scale was 95 (0.7) for the domain of Self-care, 98 (0.6) for Mobility and 96 (0.4) for Social Function, indicating excellent identical scores. The ICC values were 0.90 for Self-care, 0.96 for Mobility and 0.96 for Social Function. Agreement of the two assessments was good or excellent in all domains of the PEDI-NL-CVI used for children with CP and CVI.

For inter-respondent reliability, the mean percentage (*SD*) of identical scores for the Functional Skills scale was 21 (2.6) for the domain of Self-care, 76 (0.9) for Mobility and 23 (2.2) for Social Function, indicating poor-to-good identical scores.

For inter-respondent reliability, the mean percentage (*SD*) of identical scores for the Caregiver Assistance scale was 40 (1.8) for the domain of Self-care, 43 (5.9) for Mobility and 43 (1.2) for Social Function, indicating moderate identical scores. Further, all ICC values ranged from 0.87 to 0.99 for inter-respondent reliability (Table 5). Agreement of the two assessments was good or excellent in all domains of the PEDI-NL-CVI used for children with CP and CVI.

Cronbach's alphas for the Functional Skills scale were above 0.98 (Self-care), above 0.98 (Mobility) and above 0.97 (Social Function). Cronbach's alphas for the Caregiver Assistance scale were above 0.95 (Self-care), above 0.95 (Mobility) and above 0.88 (Social Function), indicating good or excellent internal consistency within each domain of the PEDI-NL-CVI. Cronbach's alpha for the Caregiver Assistance scale ranged from 0.94 to 0.95 (Self-care), from 0.95 to 0.96 (Mobility) and from 0.88 to 0.90 (Social Function), indicating good or excellent internal consistency within each domain of the PEDI-NL-CVI.

The mean percentage (*SD*) of identical scores for the Modifications scale was 71 (1.8) for the domain of Self-care, 89 (1.2) for Mobility and 86 (1.0) for Social Function. The ICC values were 0.55 for Self-care, 0.75 for Mobility and 0.75 for Social Function, indicated moderate-to-good agreement.

The ICC values indicated absolute agreement of the Modifications scale on three measurements for Self-care ranged from 0.87 to 0.90 (no modifications), from 0.85 to 0.91 (child-oriented modifications), from 0.23 to 0.34 (specialised rehabilitation equipment), and from 0.69 to 0.82 (extensive modifications). The ICC values indicated absolute agreement of the Modifications scale on three measurements for Mobility ranged from 0.86 to 0.92 (no modifications), from 0.91 to 0.92 (child-oriented modifications), from 0.96 to 0.97 (specialised rehabilitation equipment), and from 0.93 to 0.95 (extensive modifications). The ICC values indicated absolute agreement of the Modifications scale on three measurements for Social Function ranged from 0.94 to 0.99 (no modifications), from 0.68 to 0.71 (child-oriented modifications), from 0.83 to 0.84 (specialised rehabilitation equipment), and from 0.84 to 0.85 (extensive modifications).

Table 5

Inter-respondent reliability. Results of the Functional Skills (FS) and Caregiver Assistance (CA) scales. Summed scores: mean (*M*), standard deviation (*SD*), paired *t*-test, *p*-value, limits of agreement (LOA), percentage of identical scores, and ICC (CI) (*n* = 75).

PEDI-NL-CVI	1st interview <i>M</i> (<i>SD</i>)	2nd interview (mother or father <i>M</i> (<i>SD</i>))	<i>t</i> -value	<i>p</i> -value	Mean of difference (LOA)	% identical scores: <i>M</i> (<i>SD</i>)	ICC (LB–UB)
FS – Self-care	34 (17.5)	34 (17.0)	−1.99	0.050	−0.58 (±5.00)	21 (2.6)	0.99 (0.98–0.99)
FS – Mobility	31 (18.5)	31 (18.7)	−0.34	0.737	−0.80 (±4.02)	76 (0.9)	0.99 (0.99–1.00)
FS – Social Function	37 (14.0)	37 (14.2)	−1.45	0.151	0.36 (±4.21)	23 (2.2)	0.99 (0.98–0.99)
CA – Self-care	17 (9.3)	16 (9.0)	−3.97	0.000	−0.82 (±3.53)	40 (1.8)	0.98 (0.96–0.99)
CA – Mobility	15 (12.2)	15 (11.2)	−0.34	0.737	−0.08 (±2.74)	43 (5.9)	0.87 (0.81–0.92)
CA – Social Function	12 (4.7)	12 (4.8)	0.29	0.169	0.04 (±2.37)	43 (1.2)	0.97 (0.95–0.98)

ICC, intraclass correlation coefficient; LB, Lower Bound; UB, Upper Bound; CI, confidence interval.

4. Discussion

The aims of our study were to develop an adapted version of the PEDI-NL and to determine the inter-respondent reliability and test–retest reliability of this adapted version for children with CVI and CP. The CVI adapted version of the PEDI-NL appears to be a reliable instrument for measuring the daily skills of children with CP and CVI. The results indicate high agreement about the overall content of the adapted version of PEDI-NL. All experts agreed on the PEDI-NL-CVI for the children with CVI. From the high intraclass correlation coefficients and Cronbach's alpha's we conclude that reliability was good, not only at the scale scores but also the individual items. The results of test–retest reliability of the Functional Skills scale and the Caregiver Assistance scale indicate a good identical scores. The results of inter-respondent reliability of the Functional Skills scale and the Caregiver Assistance scale indicate poor-to-good identical scores.

4.1. Adaptation

Using the PEDI-NL-CVI for children with CVI helps measure a specific task without changing the question or instruction of original PEDI-NL. The experts suggested that 'it is assumed that the parents/caregivers use verbal and manual support to help the child perform a skill'. This is due to the fact that a child with CVI has difficulty imitating by looking, which may result in difficulty imitating actions based on visual imitation. Using verbal or manual support will help the child describe an action that occurs.

During the adaptation process, experts proposed most suggestions on the Functional Skills scale (Self-care, Mobility, Social Function) (Table 2). Less adaptation was needed on the Caregiver Assistance and Modifications scales. The experts did give suggestions for use of equipment, especially for children with CVI, and adaptation of environment such as lighting at home or at school. In line with other studies (Ghasia et al., 2008; Dutton & Jacobson, 2001; Dutton, 2013; Salavati et al., 2014; Steendam, 2007) on CVI and the experts' viewpoints, the adaptation of PEDI-NL for children with CVI was on verbal support/instruction, manual support, types of equipment and environment. Regardless of adaptations, it remains important to register the type of visual and manual support a child with CVI needs in order to accomplish a certain task and the characteristics that materials need to have (e.g. colourful, sound-produced, high in contrast) in order to receive the child's attention using specific materials. For Self-care and Mobility, our experts suggested that children need to know in advance about positions such as a leisurely pace or a toothbrush. For transfers, the child is allowed to use the arms for orientation and to use a chair with armrests. In accordance with other investigators (Wassenberg-Severijnen et al., 2003) and our experience using PEDI-NL-CVI, therapists are not familiar enough with specific Self-care activities, Social Function skills and amount of Caregiver Assistance at home (Wassenberg-Severijnen et al., 2003). For example, several therapists found it to be difficult to answer questions about 'self-protecting' or 'functioning at home' (Functional Skills scales, Social Function domain). It is therefore important to interview the parents in order to receive reliable information about these areas of functioning.

Despite the fact that for adaptation and reliability of PEDI-NL-CVI, children included with all subtypes of CVI, the researcher should take into account which type of CVI is present. Because, CVI is quite variable in its range from no light perception to normal visual acuity, and with cognitive visual dysfunction, a disorder of visual processing that leads to misinterpretation of the visual world with respect to what objects are or where they are (Edmond & Foroozan, 2006). However we cannot ensure that all subtypes are represented. Further research is needed to determine the psychometric properties of this adapted questionnaire for children with different subtypes of CVI.

Also, a familiar environment can result in successful execution of skills, in contrast to an unknown or less familiar environment. For this reason, it is important to use the PEDI-NL-CVI to evaluate the child's level of functioning at every turn, in the same environment.

There are several limitations caused by CVI that have to be taken into account when judging daily activities. Firstly, the professionals agreed that children with CVI have limitations on recognising localisation of equipment and in areas of eye-hand, eye-foot coordination, depth perception and spatial awareness, due to the fact that visual information is not processed adequately in the brain. This could result in difficulty with 'asking for help or support', as the child may not be aware of possible levels of support. This makes it difficult for the child to indicate or find a solution. Secondly, due to difficulty in the areas of spatial orientation, a child may experience limitations in finding the road in known space or finding the toilet in a known building. Furthermore, children with CVI make contact with other children differently than by using the visual system, using instead auditory (by locating the sound) or tactile (by trying to touch) perception. Thirdly, owing to the lack of depth perception, children with CVI often have difficulty with cycling and related sub-skills, such as getting on and off the bike. Cycling is a complex skill and requires proper motor skills as well as an adequate visual perception. Fourthly, children with CVI often have difficulty completing an item within the prescribed time. Likewise, 'thoroughness of washing hands' or 'drinking without spilling' will be affected by a lack of visual perception and the extent to which such a child has been taught to deal with limited visual perception. Because, CVI results in difficulties experienced with distance viewing e.g. "looking at the clock" (Social Function, time orientation), the child is allowed to use his/her (adapted) watch to check time. Lastly, doing puzzles is difficult for the child when one single colour is used for different images of the puzzle. To this end, the professionals gave some suggestions for use of adapted puzzles for children with CVI. The severity of CVI can be determined by the amount of support needed/given. In turn, a higher degree of assistance may explain the presence of the CVI. In future studies it will be important to determine the relation between the current adaptation of PEDI-NL-CVI and different types of visual impairment.

4.2. Test–retest reliability and inter-respondent reliability

Reliability of PEDI-NL (Wassenberg-Severijnen et al., 2003) is above 0.90 on a scale score for all ICC's and Cronbach's alpha above 0.88 for all domains, indicating good to excellent reliability within each domain of the PEDI-NL-CVI. This is comparable with the original study of PEDI-NL (Wassenberg-Severijnen et al., 2003). Inter-respondent reliability of the Modifications scale indicated good ICC values for all domains, except for Self-care (0.55). This could be due to the presence and use of equipment in different environments of a child, such as the home or school. However, an adapted environment may result in more use of equipment compared to an environment that is not adapted to that specific child. Table 5 shows a t -value of -3.97 ($p = 0.000$) for Self-care (Caregiver Assistance scale). However, clinically speaking the size of the difference (1.0) between the first (mean 17) and second (mean 16) interview seems small. This makes the outcome of Self-care acceptable.

In our study, the results on percentage of identical scores do not always match with those on ICC. A reason for this is that the level of agreement is close to perfect but not completely identical. If for instance, the agreement is based on 2 points above or below zero, then the percentage identical score for inter-respondent reliability, domain Self-care (Functional Skills scale) is 81 instead of 21 (mean: -0.58 and SD: 2.56), and for domain Social Function (Functional Skills scale) is 89 instead of 23 (mean: 0.36 and SD: 2.15).

The Bland and Altman plots in Figs. 2 and 3 illustrate variations around the zero line. Except for a few values, these plots demonstrate roughly equal distribution 2 points above and below the zero line for domain Self-care (Functional Skills scale) and Social Function (Functional Skills scale) with regard to inter-respondent reliability. The few higher and lower values (for Self-care SD: ± 5.00 and for Social Function SD: ± 4.21) are the scores of parents. If we compare the scores of caregiver for Self-care (Functional Skills scale) and Social Function (Functional Skills scale), with regard to test–retest reliability, the scores of the same subjects are 2 points above or below zero.

On an item score for the Functional Skills scale the PEDI-NL (Wassenberg-Severijnen et al., 2003) shows that the mean percentage identical scores were moderate to excellent. The current study of PEDI-NL-CVI indicates moderate-to-good mean percentage identical scores for test–retest reliability, and poor-to-good mean percentage identical scores for inter-respondent reliability. In accordance with other investigators (Wassenberg-Severijnen et al., 2003), when using the PEDI-NL-CVI for children with CVI it is important to interview the same parent or caregiver to ensure that differences between two measures are the result of real changes in functional status rather than the result of differences in judgement between parents or caregivers (Wassenberg-Severijnen et al., 2003).

Fig. 2. Bland and Altman plot for inter-respondent reliability of functional skills (FS), domain self-care. The mean difference is -0.58 ± 5.00 (LOA) ($-5.59; 4.41$).

Fig. 3. Bland and Altman plot for inter-responder reliability of functional skills (FS), domain social function. The difference is 0.36 ± 4.21 (LOA) ($-3.85; 4.57$).

The results of mean percentage identical scores for the Modifications scale ranged from 0.23 to 0.34 on three measurements for Self-care (specialised rehabilitation equipment), indicating poor mean percentage identical scores. This may be caused by differences in the presence of specialised rehabilitation equipment between school and home.

Our study included children with different types of CP and various degrees of severity, who might have different profiles of functional limitations in daily life. However, most participants were children with spastic CP. The reliability of the PEDI-NL-CVI could be investigated further in the group of children with different types of CP. The PEDI-NL (Wassenberg-Severijnen et al., 2003) is used for disabled children with various diagnoses, aged between 7 and 88 months. The current study investigated the PEDI-NL-CVI for children with CVI and CP, aged between 50 and 144 months, as children with CP take longer before they achieve a higher level of functional skills. We therefore assessed the PEDI-NL-CVI in a group of older children with CP and CVI.

5. Conclusion

The adapted version of PEDI-NL is a useful and reliable instrument for professionals who work with children with CP and CVI to measure functional performance in self-care, mobility and social function in these children.

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