Evaluation measures for children with cerebral palsy

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Abstract. Cerebral palsy is a well-recognized neurodevelopmental condition. The most recent definition describes cerebral palsy as a group of disorders of movement and posture, causing activity limitation. An important step in the process of (re)habilitation is evaluation of functional abilities of an individual. To be as accurate as possible in the evaluation of functioning, proper measurement instruments have to be used. There are many different measurement tools for children with cerebral palsy, several of them are presented in the article.

Key words: Measurement instruments, child, cerebral palsy

1. Introduction

Cerebral palsy (CP) is a well-recognized neurodevelopmental condition. The most recent definition describes CP as a group of disorders of movement and posture, causing activity limitation, that are attributable to non-progressive disturbances that occurred in the developing infant or fetal brain (1). The motor disorders of CP are often accompanied by disturbances of sensation, cognition, communication, perception, behavior and epilepsy. Difficulties in the complex coordinated activity of feeding may also be present in the most severe forms of CP.

An important step in the process of (re)habilitation is evaluation of functional abilities of an individual. According to the International Classification of Functioning, Disability and Health (2), functioning is an umbrella term for body functions, body structures, activities and participation. It denotes the positive aspects of interaction between an individual (with a health condition) and the individual's contextual factors (environmental and personal). Activity limitations (rather than the term 'disability') are difficulties an individual may have in executing activities. Participation limitations (rather than the term 'handicap') are problems an individual may experience in involvement in life situations (2).

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To be as accurate as possible in the evaluation of functioning, proper measurement instruments have to be used. In the process of choosing between different instruments, we have to know who we want to evaluate and what the aim of the evaluation is. It is important to choose an instrument with good psychometric properties and, if possible, the one that is widely used, so that various findings can be compared with those of other studies. It is generally not easy to develop a new instrument since that is a very time-consuming and financially demanding enterprise and requires expertise in the science of measurement development.

The European Research Group on Health Outcomes has set guidelines for cross-cultural adaptation. The adapted instrument has to meet criteria of content, semantic and conceptual equivalence (3).

There are numerous instruments already available for evaluation of children with cerebral palsy. In the following text some of them are shortly presented.

1. 1. Classification systems

There are several systems widely used to classify children with CP according to some specific feature. Traditional systems are taking into account the distributional pattern of an affected limb (like diplegia, hemiplegia) with an added modifier describing the predominant type of muscular tone (e.g. spastic, dystonic). Recently Bax and co-authors proposed four major classification dimensions (4):

- motor abnormalities
- associated impairments
- anatomic and radiological findings
- causation and timing

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Within the first dimension they proposed firstly to take into the account the nature and typology of motor disorder and secondly the functional motor abilities (4). There are several functional classification systems in the literature, most known are: The Gross Motor Classification System (5), The Manual Ability Classification System (MACS) (6), The Bimanual Fine Motor Function (BFMF) (7) and The Communication Function Classification System (CFCS) (8). Lately there was a new classification system adults introduced for children and with developmental disorder, the Dysphagia Management Staging Scale (DMSS) (9).

2. The gross motor function classification system – expanded and revised version (GMFCS - E&R)

The original GMFCS was published more than a decade ago by Palisano and co-workers (5). The classification is based on self-initiated movement with particular emphasis on sitting and walking. 5 levels of system are clinically meaningful. Distinctions between levels of motor functions are based on functional limitations, the need on assistive technology (including mobility devices such as walkers, crutches and canes) and wheeled mobility. There are precise descriptions of all five levels for different age bands: just before 2nd birthday, between 2nd and 4th birthday, between 4^{th} and 6^{th} birthday, between 6^{th} and 12^{th} birthday. Children that were prematurely born are to be considered at the corrected age when they are classified just before 2nd birthday. The focus is on what a child is usually able to perform in motor function in home, school and community settings. It is not about best capacity but ordinary performance and without judgments about quality of movement and prognosis. The scale is ordinal and with no intention that differences between levels would be considered equal or that children with CP would be equally distributed among 5 levels. The standard user instructions and complete guide to the GMFCS are available at www.fhs.mcmaster.ca/canchild.

In 2007 a revised and extended version was published (10). The aim was to refresh the original system taking into account new ideas of ICF (2). 5 levels of the expanded and revised system are based on functional distinctions that are meaningful in daily life. New is also an additional age band for youth from 12 to 18 years of age. Descriptions for 6 to 12 years and 12 to 18 years age band reflect also the impact of personal (e.g., energy demands and social preferences) and environmental factors (e.g., distances in school and home environment) on methods on mobility.

Both versions were proved to be valid and reliable (5,11-13). Both were translated in several languages and again proved to be reliable (14,15). Also high reliability of parents report was proved (16,17). This could help professionals and parents to communicate about the child's situation, its abilities, needs and prognosis.

Morris and Bartlett (18) were writing in details about the impact and utility of GMFCS. They found out that GMFCS has been used in both observational and experimental research to describe study samples and to explore the role of severity of functional limitations as an effect modifier. The GMFCS is appearing useful as a longer term outcome for perinatal and neonatal studies. The GMFCS provides a simple method for researchers to describe the functional abilities of children with CP so that clinicians can readily determine whether their patient is similar to or different from those described in a study (18). Morris and Bartlett wrote are also implications of research to clinical practice. Clinicians benefit from knowing the clinical course of children in each of the five GMFCS levels to establish likely outcomes. The impact of the GMFCS on clinical practice might begin during disclosure of the diagnosis, by using the system to help families understand a child's current abilities and prognosis, and subsequently in planning for future equipment needs and types of intervention. The GMFCS can help enormously when setting functional goals collaboratively with families. It can also be used to clarify expected outcomes with therapeutic interventions, orthoses, pharmaceutical interventions or surgery interventions for children at different levels (18). All that was written for the impact and utility of GMFCS we can assume also for MACS.

3. The manual ability classification system (MACS)

The purpose of MACS was to provide a systematic method for classification of children with CP between 4 and 18 years of age, based on their ability to handle objects in daily activities (http://www.macs.nu/index.php). Age appropriate activities and objects are to be considered. It helps us to determine the level that best corresponds with the child's usual abilities at home, at school and in the wider social environment. The level should be determined with the aid of information obtained from a person who knows the child well, not by special testing. It should represent the cooperation of

both hands in activities and not each hand separately (6).

The scale is, as in GMFCS, ordinal and with no intention that differences between levels would be considered equal or that children with CP would be equally distributed among 5 levels. Distinctions among levels are based on child's ability to handle objects and need for help or adaptations (6).

Content validity and reliability was proved for MACS (6, 19). It was also translated in some other languages and validated again (20, 21).

4. The bimanual fine motor function (BFMF)

Similarly also BFMF offers us a system for classification of children with CP from age of 4 years. It was described by Beckung et al in 2002 (7). In the BFMF, manipulation and gripping ability in both hands is classified in a five-level system. Data on validity and reliability of the BFMF has to date not been published. It is used as a classification system for Surveillance of CP in Europe (22).

5. The communication function classification system (CFCS)

The CFCS for individuals with CP is a fivelevel classification system currently under development at Michigan State University (8). Design and development of the CFCS attempts to address a number of issues in CP including a general lack of knowledge regarding the communication abilities of individuals with CP. The system is designed to be a quick and simple instrument used by a person familiar with the individual to be classified. Variables of communication ability used within the CFCS include sender roles (being able to communicate a message to someone), receiver roles (being able to understand a message from someone), pace of communication, and the degree of familiarity with a communication partner. Data on validity and reliability of the CFCS has to date not been published.

6. Dysphagia management staging scale (DMSS)

The classification in one of 5 levels is based on feeding and swallowing disorder with particular emphasis on different stages of eating and swallowing (9). Judgments of level of disorder are made on three categories of information:

Signs and symptoms of swallowing and feeding disorder: these may include reference to oral

preparation, oral initiation, pharyngeal and esophageal phases, as well as to indirect signs and symptoms, such as anorexia and rumination.

Intervention strategies that are used to manage ingestion activities including eating, drinking and taking oral medications.

Adequacy of nutrition, hydration and respiratory health as known to be related to swallowing and feeding disorder. The standard of adequacy considers both chronic and chronic intermittent effects (9).

There are also normative data available for the population of children and adults with developmental disorders. No data are yet available specifically on children with CP.

It can be used in the combination with the Dysphagia Disorder Survey (9).

7. General measurement instruments for evaluation of functioning

7. 1. Pediatric evaluation of disability inventory (PEDI)

PEDI is an instrument designed to assess capability and performance of functional activities of typically developing young children aged from 6 months to 7.5 years (23). It can be used either as a parental report or as a structured interview conducted by a rehabilitation professional. It was developed to discriminate between non-disabled and disabled children. Based on assessments of disabled children, service providers should be able to design rehabilitation programs and evaluate their efficacy (23).

PEDI measures capability and performance of functional activities in three content domains: self-care, mobility and social function (23). Capability is measured by identification of functional skills for which the child has demonstrated mastery and competence. These skills, rated on the Functional Skills Scales of the PEDI, are a direct measure of functional capability of a child, and provide sufficient detail to identify the clinical patterns of limitations in functional skill attainment. Performance of daily functional activities is measured by the level of caregiver assistance that is needed to accomplish them. The Caregiver Assistance Scale is the measure of the extent of help the caregiver provides in typical daily situations. The third part, the Modification Scale, adds to knowledge of the actual performance of functional activities. It is a measure of environmental modifications and equipment used by a child in routine daily activities. The PEDI consists of 197 functional skill items and 20 items that assess caregiver assistance and modifications (23).

7. 2. Scoring

In Part I of the PEDI, the format is dichotomous, so the questions can be scored either 'capable' or 'not capable'. A score is positive when a child has mastered a particular skill. In the Caregiver Assistance scale (Part II) there are six rank-ordered response choices, ranging from 0 (totally dependent) to 5 (independent). Every item has its own score criteria in the PEDI manual. PEDI was proved to be valid and reliable instrument (23-28). Since there is also a social function domain it is more prone to lose validity after transfer to another cultural environment. Several authors reported that normative scores are not applicable for their population of children (29-33). To summarize, the results confirming the existence of intercultural differences are a strong argument for renorming the PEDI before introducing the instrument into practice. Nevertheless, PEDI is a useful instrument for detection and evaluation of functional deficits, as well as for follow-up and assessment of efficacy of pediatric rehabilitation validity and When comparing programs. reliability of different instruments for measuring health and well-being of children with spastic form of CP, PEDI demonstrated higher internal consistency than the Pediatric Outcomes Data Collection Instrument (PODCI) and Child Health Questionnaire (33).

In comparison with the GMFM, the PEDI mobility scale detected the most significant health differences between children with hemiplegia, diplegia, and quadriplegia. The PEDI social function scale detected the largest differences in cognitive function between children with an IQ of less than 70 compared with those with an IQ of 70 or greater.

8. Functional independence measure (FIM)

The FIM (34) is an 18-item, seven level ordinal scale from independent (7) to total assistance (1). Each item is operationally defined in terms of these 7 levels. The Uniform Data System for Medical Rehabilitation (UDS) provides training materials, a shared database for participating facilities, and requires overall 80% accuracy of raters at each facility for qualifying members.

The FIM was intended to be sensitive to change in an individual over the course of a comprehensive inpatient medical rehabilitation program, aged from 7 to 99 years of age. The FIM can be completed in approximately 20-30 minutes in conference, by observation, or by telephone interview. Rasch analysis defines two FIM dimensions, labeled motor and cognitive. It was designed to assess areas of dysfunction in activities which commonly occur in individuals with any progressive, reversible or fixed neurologic, musculoskeletal and other disorders.

FIM items: eating, grooming, bathing, dressing upper body, dressing lower body, toileting, bladder management, bowel management, bed, chair, wheelchair transfer, toilet transfer, tub and shower transfer, walking/wheelchair locomotion, stairs, comprehension, expression, social interaction, problem solving and memory (34).

FIM interrater reliability in the clinical setting was reported by Hamilton et al (35). It was concluded that the 7-level FIM was reliable when used by trained/tested inpatient medical rehabilitation clinicians.

Kidd et al reported results of a study in which the FIM was compared to the Barthel Index to determine its validity, reliability and ease of use in two groups of 25 patients undergoing neurorehabilitation (36). The FIM was considered to be more valid than the Barthel Index, and equally reliable in the assessment of disability. When the two disability scores were compared using subjective and objective assessment the agreement between them was comparable, although neither was high.

9. Wee-FIM

The WeeFIM is derived from the Functional Independence Measure (FIM). It describes consistent and usual performance to criterion standards of functional skills for children ages six months to eight years. The WeeFIM includes 18 items on a seven-level ordinal scale. A score of one reflects total assistance and a score of seven reflects complete independence. The test-retest reliability and concurrent validity were tested and proved (37,38). The WeeFIM was stated as a useful tool for assessing functional status in children with neurodevelopmental disabilities (37). Its reliability and stability was also proved. examined by Equivalence reliability was comparing ratings obtained when using personal assessment with ratings collected during a telephone interview. No statistically significant differences were found for individual items, subscale scores or total WeeFIM values (39).

King et al. are reporting that while the WeeFIM adequately reflects the severity of neurological involvement in pediatric orthopedic patients, it either does not demonstrate sensitivity in those aspects of the disease treated by orthopaedists, particularly with ambulatory cerebral patients where the WeeFIM mobility scale cannot differentiate post operative changes, or the patients did not improve (40). The WeeFIM was designed to measure the burden of care, which it accurately reflects. However, in the population tested, it lacks construct validity for important issues to musculoskeletal surgery and has a significant ceiling effect in the mobility domain. They recommend against its general use in this population for assessment of mobility outcomes (40).

10. Special measurement instruments for evaluation of functioning

10. 1. The Gross motor function measure (GMFM)

The GMFM was designed and validated for children with CP and is used widely as a clinical and research outcome measure (41). The original GMFM, now referred to as the GMFM-88, is comprised of 88 items grouped into five functional dimensions: lying and rolling; sitting; crawling and kneeling; standing; walking, running and jumping. The items are arranged within dimension by difficulty. Each item is scored on a four-point rating scale from 0 to 3, with 0 indicating that the child cannot initiate the item and 3 indicating that the child can complete the item (as defined in the GMFM manual). Each of the scoring options within the 88 items is explicitly defined, in order to describe clearly the motor behavior to be observed and scored. Percent scores for each dimension are summed and averaged to obtain a total GMFM-88 score. There is considerable evidence of the reliability, validity and responsiveness of the GMFM-88 for children with cerebral palsy. Recently it was confirmed also for children with Down syndrome (42).

While the GMFM has been useful to document gross motor function in a systematic way, one limitation of the measure is that the scoring (and thus interpretation) is based on ordinal level data. The Rasch analysis of the GMFM was done and interval level measure with improved an interpretability of scores was created (43). The adaptation of the new interval-level scoring system for the GMFM-66, for children with CP, is an improvement over the GMFM-88 percent scores. Of the 88 original items, 66 have been found to contribute to a unidimensional group of items that measure gross motor function. A computer program, the GMAE, has been developed to compute reliable person ability estimates, based on the responses to these 66 items. Because the assumption of test-free measurement has been validated, not all of these items need to be tested to estimate a child's gross motor ability, however the more data available for a subject, the more accurate the estimate of gross motor function.

The use of GMFM is very wide. Lately GMFM was selected as a European consensus tool for follow-up of children treated with botulinum toxin. In the consensus GMFM and GMFCS have been expanded to provide a graphical framework on how to treat the motor disorders in children with CP. This is intended to facilitate communication between parents, therapists and medical doctors concerning (1) achievable motor function, (2) realistic goal-setting and (3) treatment perspectives for children with CP (44). It is used also in follow up of CP children after intrathecal baclofen therapy (ITB) in combination with PEDI. Ramstad reported on changes across all ICF dimensions after the TBI (456). It is used to follow up the effects of different therapy apporaches (46, 47).

10. 2. The Gross motor performance measure (GMPM)

The GMPM was developed as an observational instrument to measure changes in quality of movement in children with CP. Validity, reliability and responsiveness of this measure was investigated quite some time ago (48). Few years later it was found that the measure is differentially responsive to changes in "stable" "responsive" groups (49). and Although assessment of the quality of movement in children with CP is difficult, the development of the GMPM has facilitated this process. Interobserver reliability was in the 'fair to good' category. Reliability scores improved over time with continual use of the GMPM. A greater number of individual item scores moved from the 'fair to good' category to the 'excellent' category. Results from this study indicate that it is possible to assess reliably the quality of movement in children with CP (50).

10. 3. Assisting hand assessment (AHA)

The Assisting Hand Assessment was designed to evaluate change in assisting hand function in bimanual activity performance of children with hemiparetic CP and children with obstetric lesion of brachial plexus. AHA is conducted by observing object-related actions. A semistructured play is videotaped and then scored according to criteria in the Manual. 22 items are scored on a 4-point scale rating the quality of performance. The original Swedish version of AHA was proved to be reliable, valid and sensitive to a small change (51-53). Also most recent study (54) is presenting data about the excellent test-retest reliability of AHA. Besides, it was proved, that a change of 4 points or more between test occasions represents a significant change. It was already translated to other languages and proved to be reliable tool (55).

AHA was used in several studies for evaluation of efficacy of therapy. Elliasson et al. reported that the children who received constraint induced movement therapy (CIMT) improved their ability to use their hemiplegic hand significantly more than the children in the control group after 2 months, i.e. after treatment. Effect size was high after treatment and remained medium at 6 months (56). Also Wallen et al reported on efficacy of modified CIMT (57). To evaluate the hand function they used AHA and the Melbourne Assessment of Unilateral Upper Limb Function.

Gordon et al used the same instrument but to evaluate the hand-arm bimanual intensive therapy (HABIT), using the principles of motor learning, and neuroplasticity, to address these bimanual impairments in children with hemiplegic form of CP (58). The results suggested that for a carefully selected subgroup of children with hemiplegic CP, HABIT appears to be efficacious in improving bimanual hand use (58).

Based on data form recent study by Holmefur and co-workers AHA can be also used to discuss future development of affected hand use in bimanual tasks in children with unilateral CP (59).

10. 4. ABILHAND-Kids

The ABILHAND-Kids is a parent-report, performance-based questionnaire with excellent clinical utility and psychometric properties (60). It is a tool that was developed for measuring manual ability in children with CP. The Rasch measurement model was used. ABILHAND-kids consists of 21 mostly bimanual items. It also provides guidelines for goal setting and treatment planning. Its range and measurement precision are appropriate for clinical practice. The ABILHAND-kids measures are significantly related to school education, type of CP, and gross motor function. A high reliability and a good reproducibility over time were reported (60).

10. 5. The Quality of upper extremity skills test (QUEST)

This test was designed to evaluate the quality of upper extremity function in four domains: dissociated movement, grasp, protective extension and weight bearing. It was designed to be used with children, who exhibit neuromotor dysfunction with spasticity and has been validated with children 18 months to 8 months of age. It is a criterion referenced measure with excellent reliability. It correlates strongly with another measure of hand function, the Peabody Developmental Fine Motor Scales (61). Haga and co-workers reported that test-retest reliability was strong; intra-observer agreement and agreement between various observers were moderate to strong in preschool-age children with CP (62).

10. 6. Melbourne assessment of unilateral upper limb function

It is a quantitative test of quality of movement in children with neurological impairment. Randall et al reported results which indicate that it is a reliable tool for measuring the quality of unilateral upper-limb movement in children with CP (63). They found high internal consistency of test items and moderate to high agreement both within and between raters for all test items. Testretest results revealed moderate to high intra-rater reliability for item totals for each rater and high reliability for test totals. Reliability was proved also for French translation of a test (64). Klingels et al compared the Melbourne Assessment of Unilateral Upper Limb Function and the QUEST in hemiplegic CP (65). Both showed high reliability. Correlation interrater analysis indicated that different dimensions of upper limb function are addressed in both scales.

10. 7. Dysphagia disorders survey (DDS)

The Dysphagia Disorder Survey was developed specifically for screening adults with developmental disability for dysphagia and related eating disorders (9). However, children were included in the sample population used for standardizing the survey. Authors report on clinical experience that indicate that the DDS may be used to survey children from 2 years old to 21 years old and that the survey is appropriate for use in non-residential as well as residential populations. It identifies the relative severity and characteristics of disorder among individuals in the group thereby, aiding in setting priorities for clinical evaluations and treatments.

DDS consists of two parts: Related factors and Feeding and swallowing competency. Part 1 includes nutritional and mealtime management issues that have been found to be related to dysphagia in this population (Body Mass Index, restrictions in food texture and viscosity, dependence in eating, need for special feeding utensils to accommodate impaired oral motor competencies, need for special positioning strategies, and unstable body postures). Special feeding techniques and strategies that compensate for impairments in body postural control and swallowing and feeding capabilities, or may be unsafe or maladaptive are also considered in this section. Part 2 addresses the task components of oral preparatory, oral and pharyngeal phases of swallowing that have been found to be dysfunctional in dysphagia and unsafe eaters.

Test validity and inter-item reliability were determined on a preliminary version of the DDS in a study of 626 people with developmental disability who resided in a government-run, residential facility (9). The study included the total population of the facility. The age range was 3 to 78 years old, but the population was primarily adult. Forty-seven percent were selffeeders. The remaining 53% required assistance or were fed all their nourishments. All subjects in this study were nourished with oral feeding.

Callis and co-workers report on incidence of different severity levels of dysphagia in children with CP (66). They observed clinically apparent presence and severity of dysphagia which were with standardized assessed а mealtime observation, DDS and a dysphagia severity scale. Of all 166 participating children, 1% had no dysphagia, 8% mild dysphagia, 76% moderate to severe dysphagia, and 15% profound dysphagia, resulting in a prevalence of dysphagia of 99%. Dysphagia was positively related to severity of motor impairment, and, surprisingly, to a higher weight for height. Low frequency of parentreported feeding problems indicated that actual severity of dysphagia tended to be underestimated by parents. Proactive identification of dysphagia is warranted in this population, and feasible using a structured mealtime observation. Children with problems in the pharyngeal and esophageal phases, apparent on the DDS, should be referred for appropriate clinical evaluation of swallowing function (66).

11. Canadian occupational performance measure (COPM)

Canadian Occupational The Performance Measure is an individualized, client-centred measure designed for use by occupational therapists to detect change in a client's selfperception of occupational performance over time (67). The COPM is designed for use with clients with a variety of disabilities and across all developmental stages. It was adapted also to be used with children. It is a standardized, valid instrument (67, 68). It is designed as an outcome measure, with a semi-structured interview format and structured scoring method. Change scores between assessment and reassessment using the COPM are the most meaningful scores derived from this assessment. Originally published in

1991, with the latest fourth edition released in May 2005, the COPM has been used in more than 35 countries and has been translated into over 20 languages. The COPM has undergone extensive research in many different occupational therapy practice situations. The majority of clients and therapists indicate that the measure is easy to administer, taking 20-40 minutes.

12. The Children's assessment of participation and enjoyment (CAPE) and the preferences for activities of children (PAC)

CAPE and PAC are two companion measures of children's participation (69). Both are self-report measures of children's participation in recreation and leisure activities outside of mandated school activities. The CAPE is a 55-item questionnaire designed to examine how children and youth participate in everyday activities outside of their school classes. It provides information about five dimensions of participation, which includes diversity, intensity and enjoyment of activities. It also provides information about the context in which children and youth participate in these activities. The PAC was designed to examine children's preferences for involvement in each activity.

Both measures contain 55 activities related to children's day-to-day participation in activities outside of the school curriculum. The CAPE takes 30-45 minutes and PAC 15-20 minutes to complete. Both measures are appropriate for children and youth (with and without disabilities) between 6 and 21 years of age. Both measures demonstrated sufficient internal consistency, testretest reliability, content validity, and construct validity (69,70). Data on good internal consistency of Spanish version are also available (71).

Palisano and co-workers studied factors that influence social and community might participation of children and youth with CP (72). They also wanted to identify the types of activities in which social and community participation are highest. Participants completed CAPE and GMFCS level was determined by the researchers. They found out that youth did a higher percentage of activities with friends and others and outside the home than children. Children and youth in level I did a higher percentage of activities with friends and others compared with children and youth in levels II and III and in levels IV and V. Differences were not found between females and males. Findings cannot be attributed only to GMFCS level. Authors concluded that the ability to walk without restrictions is desirable for social and community participation. For children and youth with CP who have limitations in mobility, physical therapists have roles as consultants for accessibility, activity accommodations, and assistive technology and as advocates for inclusive environments (72).

13. Conclusion

As CP is a very diverse group of disorders of movement and posture, causing activity limitation and often accompanied by disturbances of sensation, cognition, communication, perception, behavior and epilepsy, it is also very demanding to choose a proper evaluation measure. There are many different measurers for children with CP, covering almost all ICF dimensions. By choosing the right ones it enables us to see a child with all his problems and abilities and at the same time as a whole person, who wants to participate in its social environment.

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