CASE REPORT

# Application of the ICF-CY Brief Core Set for cerebral palsy on a school age child

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## ABSTRACT

The development of the ICF Core Sets for Children and Youth with cerebral palsy (ICF-CY - CP) was published in June 2014. We describe the application of the brief core set on a 9-year-old child, in order to propose available methods and improve its applicability in clinical practice. For items that could not be described by standardized methods, we asked the patient and his family simple and objective questions. By applying the ICF-CY-CP brief core set we could demonstrate data that described the patient´s functionality objectively, as well as how contextual factors act. We concluded that the routine evaluation of these children could be expressed in a language that allows comparison and reporting for clinical, administrative, and epidemiological purposes.

**Keywords:** Cerebral Palsy, Child, International Classification of Functioning, Disability and Health

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## INTRODUCTION

The development of *Core Sets* for the *International* Classification of Functioning, Disability, and Health for children and youth with cerebral palsy (ICF-CY-CP) was conducted by Schiariti et al.[1,2] and this classification is subdivided into five *core sets* that still need to be implemented, evaluated, and validated in patients from different countries to ensure proper applicability in varied cultural, social, and economic contexts. We describe the application of this Brief *Core Set* on a 9-year old boy with cerebral palsy to show the practicality and the applicability of this classification in clinical practice.

## CASE PRESENTATION

RSO is a happy and curious 9-year old boy who likes to chat and interact with everybody. He is from the city of Franca, in the state of São Paulo, the first son of a young couple who are not blood-related, and diagnosed with diparetic spastic GMFCS IV cerebral palsy, secondary to hypoxic-ischemic encephalopathy due to prematurity, with no history of seizures. The patient was evaluated by a multiprofessional medical team during consultation in the neurology and rehabilitation services of the *Hospital das Clínicas de Ribeirão Preto* where he was evaluated according to the ICF-CY-CP.

## METHOD

To perform this evaluation we selected instruments acknowledged in the literature that could provide the qualification of each category selected for this Core Set. We asked the patient and his guardians about items that could not be qualified by specific scales in a simple and directed way, so that when a second interviewer repeated the question the answer would be the same. Items evaluated through physical examination and without specific scales were scored according to the description of the qualifier of that sub-item.

Finally, each category was qualified from 0 to 4 for body structures (s), body functions (b), and activities and participation (d). This is a negative scale where 0 represents no problem and 4, a complete problem. The descriptors for environmental factors (e) are qualified from 0 to +4 because, in this case, the scale is negative and positive, denoting the extent to which an environmental factor acts as an obstacle or a facilitator. In this scale 0 represents no barrier, .4, a full barrier, +0, no facilitator, and +4, a complete facilitator. Despite some ICF orientations recommending the use of other qualifiers that indicate the nature and location of disability for the body structures, in this work we will present only the first qualifier, regarding the intensity of the disability. Similarly, there is a recommendation for the categories of activity and participation, that the performance and capacity qualifiers be used, but only the performance qualifier will be introduced in this case report. In this way, the possibilities of response from the evaluation instruments mentioned in the next paragraphs were correlated to the ICF qualifiers.

### 1. Body functions:

**Intellectual functions** - we evaluated this item asking about his cognitive performance and school learning. The child attends the third grade in a regular school with an inclusion program. He can read words in block letters and give meaning to them, small sentences, with good diction, and interpretation. He recognizes the four basic shapes (circle, triangle, square, diamond) and can do simple addition and subtraction, using his own fingers to count.

**Sleep functions** - we applied the translated *Sleep Behavior Questionaire*.[3] On this scale, the patient scored 45 (maximum score is 130, where the higher the score, the greater the sleep-related disturbances).

**Mental functions of language -** In this item we analyzed the oral and written communication. The mother described him using the computer to write, with few spelling errors. But he also used oral language, with slight difficulty in pronouncing some phonemes.

**Seeing functions** - He was evaluated indirectly by confrontation; he wears corrective lenses for myopia, 0.5 diopters. He recognizes the borders of drawings and letters in different colors tested at a distance of approximately 1.5m, without glasses, with both eyes.

**Sensation of pain** - When questioned about pain, the child reported episodic pains in the lower limbs and in the lumbar region, graded as 4/10 on the visual analog scale. During the physical examination, he showed normal thermal, pain, and tactile sensitivity.

**Mobility of the joint functions** - Evaluated with goniometry as to hip abduction and adduction, unilateral and bilateral popliteal angle, extension and flexion of the hip and knee, and ankle dorsiflexion with knee flexion and extension.

**Muscle tone functions** - Evaluated according to the modified Ashworth scale,[4,5] with an average score of 2 (marked increase in muscle tone, expressed through the greater part of the range of motion, but the affected limb is easily moved) on the upper and lower limbs.

**Control of voluntary movement functions** - Evaluated through selective control, performing active movements as requested: dorsiflexion with knee flexion; knee extension with both limbs, unilateral hip flexion. When applying the Boyd scale[5] for selective motor control, (evaluated requesting foot dorsiflexion) the score was 2 in the lower limbs.

### 2. Activities and participation:

**Maintaining a body position** - During the physical examination, the boy could remain seated without support for three minutes.

**Fine hand use** - The MACS[6] manual classification system was used, whose scores range from 1 to 5, obtaining the value 3 (he used adapted scissors for manual activities, handled objects with both hands, exchanging hands).

**Walking** - Evaluated through observation of the gait during consultation and reviewed later through video, for classification according to the PRS scale (*Physician Rating Scale*)[7] that grades the gait from 0 to 14 (the greater the grade obtained, the better the gait pattern). The boy presented supported gait, maintaining moderate squatting, knees with moderate *recurvatum*. He also presented occasional heel-toes pattern, equinus rearfoot position in phase of contact with the ground and varus in the swing phase, and variable speed throughout the evaluation. According to the descriptors of this scale, he obtained 5 points, describing great gait difficulty.

**Moving around in different locations** - The mother was asked how the boy moved around in different locations; we learned that inside the house, he moved with great difficulty supporting himself on his upper limbs, often requiring assistance from his parents, and for outside environments, including at school, he used an adapted wheelchair, needing someone to push it because he can not reach the wheel.

**Toileting** - Evaluated through direct questioning still according to the Brazilian version of the WeeFIM (Functional Independence Measure for children).[7-9] The patient shows good bowel control and manages to undress, however, he needs aid to get to the bathroom and to clean up and dress.

**Eating** - To grade his independence for eating we use the WeeFIM. The mother reported

that the patient eats alone, using a spoon, with no need for adaptations, but requires that larger foods be cut up.

**Basic interpersonal interactions** - We asked about the patient's relationship with classmates, teachers, and friends from other institutions he attends. The boy maintains a good relationship with colleagues and teachers and understands when he is reprimanded for any error committed. His social behavior suits whatever environment he is in, according to other children his age. He also has contact and a good relationship with his grandparents, uncles, and cousins.

**Family relationships** - The boy lives with his father and mother, having a good relationship with both.

### 3. Body structures

**Structure of brain** - This item was evaluated through a tomography of the cranium to examine anatomic abnormalities in the brain, which showed a pattern of periventricular leukomalacia. This lesion occupied a very small area and therefore was considered mild.

### 4. Environmental Factors

**Products and technology for personal use in daily living** - Except for communication or mobility products, regarding products and general and assistive technology for personal use, the boy uses an adapted scissors and a spoon instead of fork and knife for eating, however this needs no adaptations. To bathe, the boy uses an adapted wheelchair and, although his toothbrush has no adaptations, he needs help from his mother to finish up. To write he uses a computer, typing preferably with the left hand, which has more dexterity. The mother denies the need for adapted toys for leisure.

**Products and technology for personal indoor and outdoor mobility and transportation** - Use of adapted wheelchair in outside environments.

**Products and technology for communication** - He uses the computer to type the words because he cannot handle a pencil well enough due to anatomical changes in his hands (tendon retractions and articular alteration in the wrist).

**Design, construction and building products and technology of buildings for public use** - The school he attends is not adapted for wheelchair users. However, the hospitals and rehabilitation center that he attends are adapted.

**Immediate Family** - The boy lives in a tranquil environment and has a good relationship with his parents, without many fights. He says he feels good when he is close to his parents, that they each help him a lot.

**Friends** - He names some school friends and talks about the games they play. He feels good in that environment, and his friends treat him with respect. His friends have no physical difficulties and help him in some simple activities when necessary.

**Social attitudes** - We evaluated this item indirectly through the responses obtained in previous descriptors, when we asked about relationships with family and classmates. We asked the mother whether the child understood when he was criticized for doing something wrong at home or at school, such as not doing a certain activity, or raising his voice to family and colleagues. She replied that her son does not behave like this frequently, but when he is corrected or scolded, he understands and apologizes for his mistakes, and usually does not repeat them. We asked the patient if he knew why he had physical difficulties, if his colleagues also presented difficulties, if they helped him in activities, if they pushed his wheelchair at school, and also if he ever heard mean comments about his physical condition at school. The boy said that his difficulties are because of a problem that occurred when he was born, demonstrating the appropriate knowledge of his condition for his age. He also reported that his colleagues did not have physical difficulties, and that they helped him in small tasks such as pushing the wheelchair and picking up objects out of his reach. He denied having heard mean comments about himself in the school environment or outside of it.

**Health services, systems and policies** - We evaluated this last item asking about services the patient uses: He has physical therapy 3 x week in a non-governmental organization has hydrotherapy 1x week and swimming 2x week. He goes for periodic follow-ups consulting in the children neurorehabilitation department in the outpatient clinic of the Rehabilitation Center of the Hospital das Clínicas de Ribeirão Preto, where he receives applications of botulinum toxin in the lower limbs approximately every six months.

**Personal factors** - The subject is a 9-year old boy, happy and curious, who likes to chat and interact with everybody, and these features help him both in conviviality with children without functional impairments and in learning new skills.

Figure 1 describes the methods used for evaluating the descriptors of the ICF-CY-CP Brief core set.

## RESULTS

Figure 2 describes the results of the application of the Brief ICF-CY-CP on this child.

## DISCUSSION

The ICF-CY-CP allows a broad evaluation of functionality. In this case report we present the application of the brief *core set* applicable to children aged from 0 to 18 years. This core set generally encompasses several aspects of the influence of body functions, of activities performed by an individual and his involvement in situations of daily living, environmental factors, personal factors, and also of structural changes in the functionality of this individual.

To reliably evaluate the functional description of these children, a multidisciplinary team is necessary that embraces many areas of health (speech pathologists, physicians, physiotherapists, occupational therapists, psychologists), as well as education and social assistance. This team of professionals must work together not only in the evaluation of the individual, but also in planning neurorehabilitation and reevaluations, to develop an evaluation that is unique and can be interpreted from several aspects describing the individual at the beginning and along its follow-ups in all aspects of neurorehabilitation, directly and positively impacting his quality of life.

Some items evaluated in the brief *core set* for children from 0 to 18 will remain unspecified in patients younger than six. Some important items to be considered in the case of adolescents are not included in the brief version, e.g. how to get, keep, and leave a job (item d845 of ICF-CY).

Another point to be considered is the assessment of the influence of body structures on functionality. In the brief *core set* this item is represented by the evaluation of brain structure, which we understand as having the greatest influence on the limitations of the evaluated individuals. However, considering the great difficulty of gait in many young people with cerebral palsy due to the motor sequelae in the central nervous system, the item structure of the lower limb, (S750) of the ICF-CY, described in the comprehensive core set of the ICF-CY-CP, could be used to better characterize the individual evaluated.

| Descriptor[10] | |
|---|---|
| Intellectual Functions | Progressive cognitive examination[11] |
| Sleep functions | Questionnaire on sleep behavior[3] |
| Mental functions of language | *"How does the child communicate? Does it presents any difficulty? Does it need a way other than speech and writing?"* |
| Seeing Functions | *"Does the child present any difficulty in seeing? Does it need corrective lenses?"* Examination of visual confrontation[11] |
| Sensation of pain | *"Does the child feel pain in any body part?"* Visual scale of pain |
| Functions of joint mobility | Physical examination of joints and their angles |
| Functions of muscle tone | ASHWORTH scale[4] |
| Functions related to the control of voluntary movements | Request to evaluate coordination of movements, diadochokinesis Boyd scale[5] |
| Maintaining the position of the body | Examination of the sitting position |
| Fine hand use | MACS scale[6] |
| Walking | PRS for lower limbs |
| Moving to different locations | *"How does the child move in environments within the home or school?"* WeeFIM scale[7] |
| Toileting | WeeFIM scale[7] |
| Eating | *"How does the child eat? Does it need any help?"* |
| Basic interpersonal interactions | *"Does the child present any difficulty relating with classmates, family, or rehabilitation professionals?"* |
| Family relationships | *"Who lives with the child? "What is the effect of their relationship on the rehabilitation of the child?"* |
| Structure of brain | Analysis of Computerized Tomography of the brain |
| Products and technology for personal use in daily living | *"How does the use of equipment for activities of daily living facilitate or hinder the life of the child?"* |
| Products and technology for personal indoor and outdoor mobility and transportation | *"Does the child need equipment to aid its locomotion? How much does this facilitate or hinder its life?"* |
| Products and technology for communication | *"How do the appliances to aid in communication facilitate or hinder the patient's life?"* |
| Design, construction and building products and technology of buildings for public use | *"Does the child need help to enter or to move around public buildings such as ramps and rails? Are these present at the health posts and public care and rehabilitation units that the child attends?"* |
| Immediate Family | "Does the child receive physical or emotional support in its relationship with parents and siblings? How does this affect its functionality?" |
| Friends | *"Does the child have friends? Do they treat the child well?"* |
| Social Attitudes | *"Does the child understand when it is chided by wrong attitudes? Does it understand its own difficulties? Does it sense when is the target of comments?"* |
| Health services, systems and policies | *"Does the child receive any type of rehabilitation? Has it undergone or is it awaiting any surgery? Does this impact functionality in any positive or negative way?"* |
| Personal factors | *"Is there any characteristic in the personality of the child? Does this affect its functionality in any positive or negative way in?"* |

*MACS- manual ability classification system; PRS- Physician Rating Scale; WeeFIM- Pediatric Functional Independence Measure*

**Figure 1.** Summary of the questions and questionnaires used to evaluate the descriptors of the Brief Core Set for children and youth with cerebral palsy

The core sets of the ICF-CY-CP do not include the individual's personal factors, but it is recommended that these be listed to provide a more complete view of functionality.[12] A classification for these descriptors is not yet established, but the insertion of the individual's positive or negative points that influence his functionality is suggested. Although there is no specific code for each characteristic, we consider it important to describe intrinsic factors related to the personality of the individual as they certainly have a great influence on their rehabilitation routine as well as on their school and family lives. The influence of environmental factors qualified in the ICF-CY-CP brief core set comprehensively demonstrate the facilities or barriers imposed by the family, school, social, and health environments in which an individual is inserted. No other instrument of functional evaluation examines these items specifically, and a detailed description of what is evaluated in each item allows less variation in responses, reducing the bias of the interviewer.

## CONCLUSION

The brief version of the ICF-CY-CP can describe the functionality of a patient in an objective manner, enabling a better evaluation of his/her evolution in the follow-up with rehabilitation. The use of traditional instruments and scales for evaluating children and youth can be transposed to the categories and qualifiers of the ICF-CY, allowing the routine evaluation of these young people to be expressed in a language that will allow comparison and preparation of reports with clinical, administrative, and epidemiological purpose.

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| | Brief ICF-CY Core Set for children and youth with cerebral palsy | The patient qualifiers | | | | | |
|---|---|---|---|---|---|---|---|
| ICF-CY code | Descriptor[10] | 0 | 1 | 2 | 3 | 4 | 8 |
| *Influence of body functions on functionality* | | | | | | | |
| b117 | Intellectual Functions | ■ | ■ | ■ | | | |
| b134 | Sleep functions | ■ | ■ | | | | |
| b167 | Mental functions of language | ■ | ■ | | | | |
| b210 | Seeing Functions | ■ | ■ | | | | |
| b280 | Sensation of pain | ■ | | | | | |
| b710 | Functions of joint mobility | ■ | ■ | ■ | ■ | | |
| b735 | Functions of muscle tone | ■ | ■ | ■ | ■ | | |
| b760 | Functions related to the control of voluntary movements | ■ | ■ | ■ | | | |
| *Influence of activities and participation on functionality* | | | | | | | |
| d415 | Maintaining the body position | ■ | ■ | ■ | | | |
| d440 | Fine hand use | ■ | ■ | ■ | | | |
| d450 | Walking | ■ | ■ | ■ | ■ | | |
| d460 | Moving to different locations | ■ | ■ | ■ | ■ | | |
| d530 | Toileting | ■ | ■ | ■ | ■ | ■ | |
| d550 | Eating | ■ | ■ | | | | |
| d710 | Basic interpersonal interactions | ■ | | | | | |
| d760 | Family relationships | ■ | ■ | | | | |
| *Influence of the body structure on functionality* | | | | | | | |
| s110 | Structure of brain | ■ | ■ | | | | |
| *Influence of environmental factors on functionality* | | Facilitator | | | | Barrier | |
| | | 4+ | 3+ | 2+ | 1+ | 0 | 1 | 2 | 3 | 4 |
| e115 | Products and technology for personal use in daily living | | | ■ | ■ | ■ | | | | |
| e120 | Products and technology for personal indoor and outdoor mobility and transportation | | ■ | ■ | ■ | ■ | | | | |
| e125 | Products and technology for communication | | | | ■ | ■ | | | | |
| e150 | Design, construction and building products and technology of buildings for public use | | | | | ■ | ■ | ■ | | |
| e310 | Immediate Family | | ■ | ■ | ■ | ■ | | | | |
| e320 | Friends | | | ■ | ■ | ■ | | | | |
| e460 | Social Attitudes | | | ■ | ■ | ■ | | | | |
| e580 | Health services, systems and policies | | ■ | ■ | ■ | ■ | | | | |
| *Influence of personal factors on functionality* | | Positive | | | | Negative | | | | |
| | | + | | | 0 | | | – | | |
| pf* | Curious | ■ | ■ | | | | | | | |
| pf | He likes to chat and interact | ■ | ■ | | | | | | | |

**pf- personal factor- item not classified by the ICF*

**Figure 2.** Descriptors qualified according to the subject's evaluation

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# Work Submission

## Presentation

The Acta Fisiátrica Journal (ISSN 0104-7795 Print/ISSN 2317-0190 Online) is a quarterly publication from the Physical Medicine and Rehabilitation Institute at the Hospital das Clínicas and from the Department of Legal Medicine, Medical Ethics, Social Medicine and Labor at the University of São Paulo School of Medicine, and it has the support of the Fundação Faculdade de Medicina/School of Medicine Foundation and of the Rede de Reabilitação Lucy Montoro/ Lucy Montoro Rehabilitation Network.

The Acta Fisiátrica Journal is primarily a publication directed to expand the knowledge of the Brazilian community involved in rehabilitation, always giving preference to articles produced in Brazil, however, authors from other countries may also forward their scientific production to us, for the journal understands that foreign contributions can supply new approaches to the problems faced in this country.

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All the content of the article must be included in the publication management system. Figures, charts, and tables are accepted and must be labeled in the text by their sequence number and location where they will be placed. If the illustrations sent have already been published, the source must be mentioned. Works that have been consulted and mentioned in the text are the responsibility of the author. Information stemming from personal communications, work in progress, and not yet published must not be included in the reference list, but indicated on a footnote on the page where they are mentioned.

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Whenever possible, the results must be presented in tables or figures. Tables are non-discursive forms of showing information, from which the numerical data stands as the central information. Prepared to be self-explanatory and with statistical analysis, tables must be limited and numbered consecutively, with Arabic numbers in accordance with the order in which they are mentioned. They must come in individual and separate sheets, with indication of their localization in the text. The title of the table is placed on the upper part, written in capital letters, respecting the grammar rules of the language. Charts are different from tables because they present a schematic and descriptive content that is not statistical. The presentation of charts is similar to that of tables, except for the placement of vertical lines along their sides and in the separation of categories. A figure is a generic denomination attributed to graphics, photographs, engravings, maps, plans, drawings, or other illustrative forms. They must be numbered consecutively with Arabic numbers under the generic denomination of Figure and must have clear legends below the frame, being indicated in sequential order.

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This must explore appropriately and objectively the results discussed in the light of other observations already recorded in the literature.

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They can register acknowledgements in a paragraph no greater than three lines, directed to the institutions or individuals that effectively contributed to the work.

**Research involving humans**
Results from studies related to humans must be accompanied by the Ethics Committee opinion from the original Institution or by another institution credentialed by the National Health Council. In addition, it must contain, in the last paragraph of the Methods section, a clear declaration of the fulfillment of the ethical principles contained in the Helsinki Declaration (2000), in addition to conforming to the specific laws of the country in which the research was conducted. The identification number of the study in the Clinical Trials Registry must be given after the abstract.

### Bibliographical citations in the text

These must be placed in numerical order, in Arabic figures, one-half line above and after the citation and must be in the reference list. In the case of 2 (two) authors, both are mentioned connected by "&," and in the case of more than 2 (two) authors, the first must be mentioned followed by the Latin expression "et al".

### References

These must be numbered consecutively, following the order in which they were mentioned the first time in the text, based on the Vancouver style. In the references from 2 (two) to 6 (six) authors, all the authors are mentioned; if there are more than 6 (six) authors, the first 6 (six) authors shall be mentioned, followed by the Latin expression "et al". The titles of periodicals must be referred-to in abbreviated form, in accordance with the "List of journals indexed in index medicus" from the National Library of Medicine.

## EXAMPLES

### Books

Murray PR, Rosenthal KS, Kobayashi GS, Pfaller MA. Medical microbiology. 4th ed. St. Louis: Mosby; 2002.

### Chapters of books

Meltzer PS, Kallioniemi A, Trent JM. Chromosome alterations in human solid tumors. In: Vogelstein B, Kinzler KW, editors. The genetic basis of human cancer. New York: McGraw-Hill; 2002. p. 93-113.

### Dissertations and theses

Borkowski MM. Infant sleep and feeding: a telephone survey of Hispanic Americans [dissertation]. Mount Pleasant (MI): Central Michigan University; 2002.

### Articles from periodicals

Halpern SD, Ubel PA, Caplan AL. Solid-organ transplantation in HIV-infected patients. N Engl J Med. 2002 Jul 25;347(4):284-7.

Rose ME, Huerbin MB, Melick J, Marion DW, Palmer AM, Schiding JK, et al. Regulation of interstitial excitatory amino acid concentrations after cortical contusion injury. Brain Res. 2002;935(1-2):40-6.

### Articles from electronic periodicals

Abood S. Quality improvement initiative in nursing homes: the ANA acts in an advisory role. Am J Nurs [serial on the Internet]. 2002 Jun [cited 2002 Aug 12];102(6). Available from: http://www.nursingworld.org/AJN/2002/june/Wawatch.htm

### For other examples, see

http://www.nlm.nih.gov/bsd/uniform_requirements.html