

International Classification of Functioning, Disability and Health Core Sets for children and youth with CP: contributions to clinical practice

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SIR—We thank Dr Virginia Wright for her comments on our paper.¹ We would like to take this opportunity to respond to some issues raised in her letter.²

The international community has embraced the International Classification of Functioning, Disability and Health (ICF) model;³ however, the extensiveness of the classification has made it challenging to apply in everyday practice. Therefore, there was a need for user-friendly ICF-based tools like the ICF Core Sets.⁴ An ICF Core Set is a list of ICF categories that serves as an international standard for describing functioning. Importantly, the ICF Core Sets summarize what should be measured and reported in a given population.⁵ The ICF Core Sets for children and youth with cerebral palsy (CP) are the first pediatric ICF Core Sets and were developed using the World Health Organization (WHO)-endorsed scientific process.¹

The contribution of the ICF Core Sets for children and youth with CP to clinical practice is manifold. First, they offer a 'framework' for guiding the functional assessment, evaluation, and follow-up of children and youth with CP worldwide. Second, the ICF Core Sets for children and youth with CP not only reflect the perspectives of professionals from the health, education, and social sectors, from all six WHO regions, but also the valuable perspectives of children and youth with CP and their caregivers.^{6–10} Finally, the five ICF Core Sets for children and youth with CP capture the developmental trajectory that children and youth with CP transition from birth to young adults, facilitating the characterization of the functional trajectory of this population over time.

We would like to respond to specific points raised in Dr Wright's letter, as follows:

(1) ICF Core Sets and quality of life (QOL). The construct of QOL is not included in the WHO's ICF. Notably, a child's functional abilities, which can be described using the ICF Core Sets, and how a child feels about his life or health (QOL),¹¹ are different constructs. As noted in the paper, we encourage the

inclusion of the child's personal assessment about his abilities in meaningful goal-setting when planning interventions.

- (2) Personal factors. The WHO has not yet assigned ICF categories to the component 'personal factors'; however, we encourage users to systematically collect information on relevant personal factors when applying the ICF Core Sets in practice (Appendix SI, online).¹
- (3) Content of age-specific Core Sets. The main differences between the age-specific Core Sets are in the component activities and participation, with higher representation as children grow older. Of note, areas of play and recreation/leisure are included in all age-specific Core Sets. Some areas of functioning are partially represented in these age-specific Core Sets, having acknowledged this limitation in our paper; we expect that the day-to-day application of the Core Sets will guide future revisions.
- (4) Cultural bias. There are ongoing initiatives in middle- and low-income countries to validate the content of the ICF Core Sets which will aid in ensuring optimal applicability across social, cultural, and economic contexts.
- (5) Clinical applications. In our paper, we illustrate a practical application of the ICF Core Sets to inform the functional profile of a child or youth with CP. The ICF Core Sets are neither assessment instruments nor a 'scale', but rather a tool that professionals can use to guide the assessment process and not overlook important areas of functioning. Using the Core Sets to define a minimal set of measures for consideration by clinicians is work already underway with support from an American Academy for Cerebral Palsy and Developmental Medicine research grant.
- (6) ICF Core Sets and family-centred care. In clinical practice, the ICF promotes family-centred care. The development of the ICF Core Sets for children and youth with CP paid special attention to the children and youth and their caregivers' opinions.⁸ The families' perspectives should be routinely addressed when setting goals for interventions which might result in higher satisfaction and better adherence to treatments.^{8,10}

Finally, the ICF Core Sets for children and youth with CP highlight 'what' to measure, not 'how' to measure in relevant areas of functioning in CP. We agree with

Dr Wright that there is a lot of work ahead to operationalize the Core Sets. The development of the ICF Core Sets for children and youth with CP has been a truly international collaboration and we look forward to further collaboration to build on this work.

SUPPORTING INFORMATION

The following additional material may be found online:

Appendix SI: ICF core sets for children and youth with cerebral palsy user instructions.

REFERENCES

1. Schiari V, Selb M, Cieza A, O'Donnell M. International Classification of Functioning, Disability and Health Core Sets for children and youth with cerebral palsy: a consensus meeting. *Dev Med Child Neurol* 2014. Doi: 10.1111/dmcn.12551. [Epub ahead of print].
2. Wright FV. What needs to happen before an International Classification of Functioning, Disability and Health Core Set is ready for clinical use? *Dev Med Child Neurol* 2014. Doi: 10.1111/dmcn.12566. [Epub ahead of print].
3. World Health Organization. International Classification of Functioning, Disability and Health: Children & Youth version. Geneva: WHO, 2007.
4. Selb M, Escorpizo R, Kostanjsek N, Stucki G, Ustün B, Cieza A. A guide on how to develop an International Classification of Functioning, Disability and Health core set. *Eur J Phys Rehabil Med* 2014. [Epub ahead of print].
5. Bickenbach J, Cieza A, Rauch A, Stucki G, editors. ICF Core Sets: Manual for Clinical Practice. ICF Core Sets. Manual for Clinical Practice. Göttingen: Hogrefe, 2012.
6. Schiari V, Klassen AF, Cieza A, et al. Comparing contents of outcome measures in Cerebral Palsy using the International Classification of Functioning (ICF-CY): a systematic review. *Europ J Paediatr Neurol* 2014; **18**: 1–12.
7. Schiari V, Mäse LC, Cieza A, et al. Toward the development of the International Classification of Functioning Core Sets for children with cerebral palsy: a global expert survey. *J Child Neurol* 2014; **29**: 582–91.
8. Schiari V, Sauve K, Klassen AF, Cieza A, O'Donnell M, Mäse LC. 'He does not see himself as being different': the perspectives of children and caregivers on relevant areas of functioning in cerebral palsy. *Dev Med Child Neurol* 2014; **56**: 853–61.
9. Schiari V, Mäse LC. Relevant areas of functioning in children with cerebral palsy based on the International Classification of Functioning: a clinical perspective. *J Child Neurol* 2014. [Epub ahead of print].
10. Schiari V, Mäse LC. Identifying relevant areas of functioning in children and youth with cerebral palsy using the ICF-CY coding system: from whose perspective? *Europ J Paediatr Neurol* 2014; **18**: 609–17.
11. World Health Organization. WHOQOL User Manual. Geneva: WHO, 1998.