

International Classification of Functioning, Disability and Health (ICF) Core Sets for childhood-onset disabilities: benefits of standardizing functional information

Schiariti et al. argue ICF Core Sets can help improve communication between users, accelerate sharing of information, and encourage swift implementation of effective interventions.

EDITOR – [Our paper explored the specificity of the content of the International Classification of Functioning, Disability and Health \(ICF\) Core Sets available for cerebral palsy \(CP\), autism spectrum disorder \(ASD\), and attention-deficit/hyperactivity disorder \(ADHD\).](#)¹ [Dr Kraus de Camargo challenged the contributions of standardizing functional information by using the ICF Core Sets for CP, ASD, and ADHD.](#)²

What we know: ICF and ICF Core Sets

To standardize the description of functional abilities, health, and disabilities of individuals in a context of a health condition, the World Health Organization created the ICF as a reference family classification.³ The ICF offers a comprehensive framework for understanding functioning and disability from a dynamic bio-psycho-social perspective.

To facilitate the application of the ICF in day to day practice, shorter and more user-friendly ICF-based tools, so called ICF Core Sets, have been developed. The ICF Core Sets represent shortlists of ICF categories that cover the most relevant areas of functioning and disability in a specific condition. To date, ICF Core Sets have been developed for three childhood onset-disabilities such as CP,⁴ ASD,⁵ and ADHD.⁶ Of note, the development of these Core Sets included the perspectives of clinicians, researchers, and stakeholders - including the clients themselves.

The ICF Core Sets have the same applications as the ICF.^{1,3} They can be used as a common language and data standard, as a framework for service provision, and policy development, among others. They can be used both at the individual and population level. The ICF Core Sets are meant to be living tools, therefore they will evolve and be revised as needed.

What this paper adds: ICF Core Sets for childhood-onset disabilities

As we described in our paper,¹ the specificity of the content of ICF Core Sets for childhood-onset disabilities have been challenged in the past. However, we have shown that each ICF Core Set for CP, ASD, and ADHD capture unique functional information as well as the unique role of environmental factors influencing functioning and disability in these populations.

The global application of these ICF Core Sets will enhance our understanding of the functional abilities of CP, ASD, and ADHD as well as complement diagnostic information with much needed meaningful functional data.

What is up for debate: ICF standardization versus ICF individualized profile of functioning

While the ICF Core Sets standardize the description of functioning and disability for individuals with CP, ASD, and ADHD, the ICF categories and codes included in the Core Sets do not intend to replace or dismiss the preferences, choices, and interests of any child or adult with CP, ASD, or ADHD.

As explained in our paper,¹ the ICF Core Sets allow building a profile of functioning and consequently collaboratively with the clients and the families set goals for intervention. Users can add ICF categories to the ICF Core Sets or choose to use a selection of ICF categories from the proposed Core Sets – to incorporate unique aspects of their patients.

Standardizing functional information regarding individuals with childhood-onset disabilities will improve communication between users, such as clinicians, researchers, administrators, policy-makers and clients. It has the potential to improve service delivery, accelerate sharing of information, and promote rapid adoption of effective interventions.

It is important to note that standardization does not prevent individualization of data collection or care. In our opinion, standardization of functional information – by applying the ICF Core Sets – ensures that professionals and families incorporate a bio-psycho-social approach, systematically addressing social domains and the crucial role of contextual factors facilitating everyday functioning.

What is going on: applications of the ICF Core Sets in pediatric settings

Since the publication of the ICF Core Sets for children and youth with CP in 2015, cultural validations have been conducted in Iran, India, Pakistan, Poland, and Taiwan – from the professionals’ and clients’ perspectives.^{7,8} Importantly, these Core Sets are open access and are available in many languages.

Implementation of the Core Sets for CP has taken place in different countries in clinical practice and research initiatives, for example: (1) guiding the description of functioning and disability in children affected by congenital ZIKA virus in Brazil,^{9,10} (2) guiding service provision in a community-based rehabilitation program in Malawi,¹⁰ and rehabilitation centers in Poland and Russia (project endorsed by the Ministry of Labour and Social Protection).¹⁰ In research, two projects identified valid and reliable measures aligning with the content of the ICF Core Sets for CP, guiding the selection of measures for evaluating chronic pain and overall functioning in CP.^{11,12}

Moreover, numerous educational activities have been conducted to facilitate the adoption of these Core Sets, including an interactive open access website called *ICF Educational e-Tool* (http://learn.phsa.ca/shhc/icf/story_html5.html).

On the other hand, the ICF Core Sets for ASD and ADHD are newly developed, uptake and implementation will take time, we expect that many initiatives will adopt these Core Sets soon.

What is needed: global collaboration to move forward

From our experience, the ICF Core Sets for CP, ASD, and ADHD have been well received by the international community. The main challenge preventing the universal adoption of these tools remains the practical operationalization of the Core Sets. Specifically, the consistent assignment of ICF qualifiers to each ICF category. At the moment, ICF users rely on clinical judgement to translate scores of standardized measures, clinical observations, and/or results of technical examinations, into the generic ICF qualifiers. Global collaboration among measurement experts, software designers, and ICF users is needed to solve this challenge.

Lessons learned from global applications of the ICF Core Sets and a shared responsibility of reporting usage – describing benefits and challenges from all stakeholders’ perspectives – will allow us to move forward.

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References

1. Schiariti V, Mahdi S, Bölte S. International Classification of Functioning, Disability and Health Core Sets for cerebral palsy, autism spectrum disorder, and attention-deficit-hyperactivity disorder. *Dev Med Child Neurol* 2018; **60**: 933–41.
2. Kraus de Camargo O. International Classification of Functioning, Disability and Health Core Sets: moving forward. *Dev Med Child Neurol* 2018; **60**: 857–8.
3. World Health Organization. International Classification of Functioning, Disability and Health: ICF. Geneva: World Health Organization; 2001.
4. Schiariti 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* 2015; **57**: 149–58.

5. Bölte S, Mahdi S, de Vries PJ, et al. The Gestalt of Functioning in Autism Spectrum Disorder: Results of the International Conference to Develop Final Consensus ICF Core Sets. *Autism* 2018 doi: 10.1177/1362361318755522. [Epub ahead of print]
6. Bölte S, de Schipper E, Holtmann M, et al. Development of ICF Core Sets to standardize assessment of functioning and impairment in ADHD: the path ahead. *Eur Child Adolesc Psychiatry* 2017; **23**: 1139–48.
7. Raji P, Hassani Mehraban A, Aliabadi F, Ahmadi M, Schiariti V. Content validity of the comprehensive ICF Core Set for children with cerebral palsy aged 0-6 years: Iranian occupational therapists perspective. *Iran J Child Neurol* 2018; **12**: 40–58.
8. Schiariti V, Ibrahim SH, Bhattacharya A, Król M. ICF Core Sets for children and youth with cerebral palsy: embracing cultural differences. WHOIC Annual report. 2016. Tokyo, Japan. Available at www.who.int/classifications/network/2017_WHOIC_Poster_Booklet.zip?ua, (accessed 15 March 2018).
9. Ferreira HNC, Schiariti V, Regalado ICR, et al. Functioning and Disability Profile of Children with Microcephaly Associated with Congenital Zika Virus Infection. *Int J Environ Res Public Health* 2018; **15**: pii: E1107.
10. Schiariti V, Longo E, Shoshmin A, et al. Implementation of the International Classification of Functioning, Disability, and Health (ICF) Core Sets for children and youth with cerebral palsy: global initiatives promoting optimal functioning. *Int J Environ Res Public Health*; **15**: pii: E1899.
11. Schiariti V, Oberlander TF. Evaluating pain in cerebral palsy: comparing assessment tools using the International Classification of Functioning, Disability and Health. *Disabil Rehabil* 2018; doi: 10.1080/09638288.2018.1472818. [Epub ahead of print].
12. Schiariti V, Tatla S, Sauve K, O'Donnell M. Toolbox of multiple-item measures aligning with the ICF Core Sets for children and youth with cerebral palsy. *Eur J Paediatr Neurol* 2017; **21**: 252–63.