

See discussions, stats, and author profiles for this publication at: <https://www.researchgate.net/publication/364638751>

The development of the International Classification of Functioning, Disability and Health for Child and Youth (ICF-CY) Core Sets: a systematic review

Article in *Disability and Rehabilitation* · October 2022

DOI: 10.1080/09638288.2022.2136269

CITATION

1

READS

50

11 authors, including:



Marco Tofani

Sapienza University of Rome

126 PUBLICATIONS 1,361 CITATIONS

[SEE PROFILE](#)



Emanuela Tiozzo

54 PUBLICATIONS 310 CITATIONS

[SEE PROFILE](#)



Immacolata Dall'Oglio

Ospedale Pediatrico Bambino Gesù

54 PUBLICATIONS 361 CITATIONS

[SEE PROFILE](#)



Michele Salata

Ospedale Pediatrico Bambino Gesù

15 PUBLICATIONS 91 CITATIONS

[SEE PROFILE](#)

Some of the authors of this publication are also working on these related projects:



EMPATHIC project [View project](#)



Ricerca-Azione nell'area Bastogi di Roma [View project](#)



The development of the International Classification of Functioning, Disability and Health for Child and Youth (ICF-CY) Core Sets: a systematic review

Marco Tofani, Martina Mustari, Emanuela Tiozzo, Immacolata Dall'Oglio, Daniela Morelli, Orsola Gawronsky, Michele Salata, Laura Cantonetti, Enrico Castelli, Domenico Di Lallo & Massimiliano Raponi

To cite this article: Marco Tofani, Martina Mustari, Emanuela Tiozzo, Immacolata Dall'Oglio, Daniela Morelli, Orsola Gawronsky, Michele Salata, Laura Cantonetti, Enrico Castelli, Domenico Di Lallo & Massimiliano Raponi (2022): The development of the International Classification of Functioning, Disability and Health for Child and Youth (ICF-CY) Core Sets: a systematic review, *Disability and Rehabilitation*, DOI: [10.1080/09638288.2022.2136269](https://doi.org/10.1080/09638288.2022.2136269)

To link to this article: <https://doi.org/10.1080/09638288.2022.2136269>



Published online: 22 Oct 2022.



Submit your article to this journal [↗](#)



Article views: 21



View related articles [↗](#)



View Crossmark data [↗](#)

REVIEW



The development of the International Classification of Functioning, Disability and Health for Child and Youth (ICF-CY) Core Sets: a systematic review

Marco Tofani^a , Martina Mustari^a , Emanuela Tiozzo^a , Immacolata Dall'Oglio^a , Daniela Morelli^a,
Orsola Gawronsky^a , Michele Salata^b, Laura Cantonetti^c, Enrico Castelli^c , Domenico Di Lallo^d and
Massimiliano Raponi^d

^aProfessional Development, Continuous Education and Research Service, Bambino Gesù Children Hospital IRCCS, Rome, Italy; ^bCenter for Pediatric Palliative Care, Bambino Gesù Children Hospital IRCCS, Rome, Italy; ^cDepartment of Intensive Neurorehabilitation and Robotics, Bambino Gesù Children Hospital, Rome, Italy; ^dBambino Gesù Children Hospital IRCCS, Rome, Italy

ABSTRACT

Purpose: The aim of this systematic review is to verify the development of the International Classification of Functioning, Disability and Health for Child and Youth (ICF-CY), investigating methodology and how many core sets have been created.

Methods: Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines were used to carry out the systematic review. Six bibliographic databases were searched: MEDLINE, SCOPUS, Web of Sciences, CINAHL, PEDro, and OT Seeker. Papers included in the study have the following characteristics: (a) pediatric population with different health conditions, (b) assessment of ICF domains, (c) development of ICF-CY core set in different health conditions, and (d) recommendation for clinical uses.

Results: Search strategies allowed to identify 270 research papers. After the elimination of duplicates, 154 articles were analyzed. Finally, 28 records were included for qualitative synthesis. Twelve different ICF-CY Core Sets were identified. Autism spectrum disorder, attention-deficit/hyperactivity disorder, and cerebral palsy were the main health conditions studied at international level. Most of the studies involved international experts using Cieza' methodology to inform ICF-CY Core Set.

Conclusions: After 15 years since the adoption of ICF-CY, it still finds some barriers to use. Concrete actions should be taken to develop further core sets following a rigorous methodology and to contribute implementing the ICF framework.

ARTICLE HISTORY

Received 16 June 2022
Revised 5 October 2022
Accepted 9 October 2022

KEYWORDS

International Classification of Functioning Disability and Health; ICF-CY; children; youth; core set; systematic review; disability

► IMPLICATION FOR REHABILITATION

- In 15 years since the implementation of International Classification of Functioning, Disability and Health for Child and Youth (ICF-CY), only 12 core sets have been developed.
- To develop ICF-CY Core Set, health professionals should follow methodology described by Cieza et al.
- Strong collaboration between low- and middle-income countries and high-income countries are recommended.

Introduction

The World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) [1] was developed to serve as a comprehensive framework for the components of functioning and disability for all health-related conditions. The ICF is designed to be used in combination with the International Classification of Diseases and health-related problems (ICD) [2]. While the ICD maps health conditions to generic categories and views disability as a consequence of a health condition (biomedical model), the ICF is based on a bio-psycho-social model of functioning, which understands disability as a result of a health condition interacting with personal and environmental factors yielding certain levels and compositions of participation and activities. Disability is therefore not an attribute of the person, but rather the result of the interaction between biological, psycho-social, and environmental contingencies [3].

The ICF provides detailed classifications of ability and disability in the areas of body functions (i.e., physiological functions of body systems), body structures (i.e., anatomical parts of the body), activities (i.e., execution of tasks), participation (i.e., involvement in life situations), and environmental factors (i.e., physical, social, and attitudinal environment). For each of these components, aspects of functioning are described in hierarchically structured categories with up to four levels of increasing detail. Therefore, within each component, there is an exhaustive list of ICF categories that serve as the units of the classification. ICF categories are denoted by unique alphanumeric codes and are hierarchically organized in chapter, second, third, and fourth levels. When going from the chapter level to the fourth level, the category's definition becomes more detailed [4]. The ICF contains more than 1400 categories, making it a highly comprehensive classification. This comprehensiveness is a major advantage and strength of the ICF. It is, however, also the biggest challenge to its practicability [1]. To

enhance the applicability of the classification, ICF-based tools must to be tailored to the needs of the users – without weakening the strengths of the ICF [5]. The ICF was approved at the 54th World Health Assembly in May 2001 and in 2007 the version for Children and Youth (ICF-CY) was adopted as well. Derived from the ICF in 2007, the ICF-CY [6] was designed to capture the particular situation of the developing child by adding categories and expanding on descriptions that specifically take into account the fact that (a) the child needs to be viewed in the context of the family; (b) the nature and forms of participation change dramatically from dependent relationships in infancy to complex life situations in adolescence; (c) along with developmental changes in participation, the nature and number of environments change as well; and (d) lags in emergence of functions or acquisition of skills may reflect developmental delay rather than impairments or stable limitations [7].

The ICF-CY consists of 1685 categories. This comprehensiveness limits the utility of the ICF-CY in daily clinical practice and research activities [6]. Moreover, to facilitate its application, the strategy for using the ICF must be tailored to the needs of different users. Due to its complexity, the ICF-CY can be challenging to apply in clinical practice. To reduce this complexity, researchers and clinicians have emphasized the importance of preselecting ICF-CY domains and codes relevant to clients with a restricted health condition. This need for individualization is the primary motivation behind the development of the ICF Core Sets [8]. An ICF Core Set is a shortlist of ICF categories that are considered most relevant for describing the functioning of an individual with a particular health condition. The development of ICF Core Sets draws on an evidence-based methodology to identify the most relevant categories from the entire classification [9,10]. Each ICF Core Set development project includes the development and selection of sets standard categories for multiprofessional comprehensive assessment (comprehensive core set) or a minimal standard for the assessment and reporting of functioning and health for clinical studies and clinical encounters (brief core set). The Comprehensive ICF Core Set is intended for use in interdisciplinary assessments, to promote the ICF as a “common language” for effective teamwork [5]. The Brief ICF Core Set is derived from the comprehensive set and can be employed in regular clinical encounters where only a brief assessment is necessary, and in clinical and epidemiological research. While a Comprehensive ICF Core Set should include the typical spectrum of problems in functioning in patients with a condition or in a defined context, the Brief ICF Core Set aims to include only the most important categories across cultures and countries to be practical in any situation or setting. ICF Core Sets can be used to help understand clients’ needs, to assess and report client functioning in different settings, and in intervention planning [11,12].

Cerniauskaite et al. reviewed all articles on ICF published from 2001 to 2009, and reported that 54 articles were devoted to studying core sets [13], while Yen et al. [14] investigated specific development of ICF core set in adult population. Results are highlighted that the majority of publications (30.8%) were conceptual papers, methodology were not univocal and strengthen the need of ICF Core Set for specific health conditions. To the best of author knowledge, only a systematic review was published for the ICF-CY version; in particular, the study of Moretti et al. [15] investigated the applicability of the ICF-CY in education reporting that ICF-CY is currently used as a research tool, theoretical framework, and tool for implementing educational processes.

This year marks the 15th anniversary from the publication of the ICF-CY, considering the importance of ICF-CY Core Set for

research and clinical practice, the present study has as objective to verify how many Core Sets of ICF-CY have been developed so far, their methodology and main findings at international level.

Materials and methods

A research group comprised of allied healthcare professionals and medical doctors from the Bambino Gesù Children’s Hospital IRCCS conducted this study. The present investigation follows the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines [16]. PRISMA is an evidence-based minimum set of items for reporting in systematic reviews and meta-analyses. PRISMA focuses on reporting of reviews randomized trials but can also be used as a basis for reporting systematic reviews of other types of research, particularly evaluations of interventions.

Protocol registration

The present systematic review was registered to PROSPERO database. The protocol was accepted in 13 April 2022 (code CRD42022301739), it is available at PROSPERO website. It is an international database of prospectively registered systematic reviews in health and social care, welfare, public health, education, crime, justice, and international development, where there is a health-related outcome.

Literature search

A comprehensive search strategy was performed using different databases, namely MEDLINE, SCOPUS, CINAHL, Web of Sciences, PEDro, and OT Seeker. As recommended by the Cochrane methodology [17], the search strategy was performed from inception until 31 January 2022. Search strategies for different database were reported as follows: (International Classification of Functioning, Disability and Health[MeSH Terms]) AND (Child[MeSH Terms]) AND (Adolescent[MeSH Terms]) AND (Core set) NOT (Adult[MeSH Terms]) NOT (Aged[MeSH Terms]). The search strategy was adjusted for each database with regard to filters or limits.

Inclusion criteria and data extraction

As mentioned before, the purpose of the present systematic review was to critical appraise, compare methodology, and summarize the ICF core set for children and youth. Therefore, general inclusion criteria were defined following the extended PICO format: patient: pediatric aged population with different health conditions. Intervention: assessment of ICF domains, namely body function and structure, activity and participation and contextual factors. Comparison: no comparator. Outcome: development of ICF-CY core set in different health conditions and recommendation for clinical uses. Study design: cross-sectional study, methodological study, validation/psychometric study.

Additionally, no language restriction has been imposed. Observational studies, clinical trials, posters, and dissertations were excluded. Two allied healthcare professionals (TM, MM) first screened one database each, by reading title and abstract. Then, to guarantee an independent and unconditional review process, each researcher evaluated the full texts primarily selected by the other. In case no agreement was achieved between the two primary reviewers, a third and fourth reviewer made decision on articles’ inclusion (ET, DD). This process led to select articles to

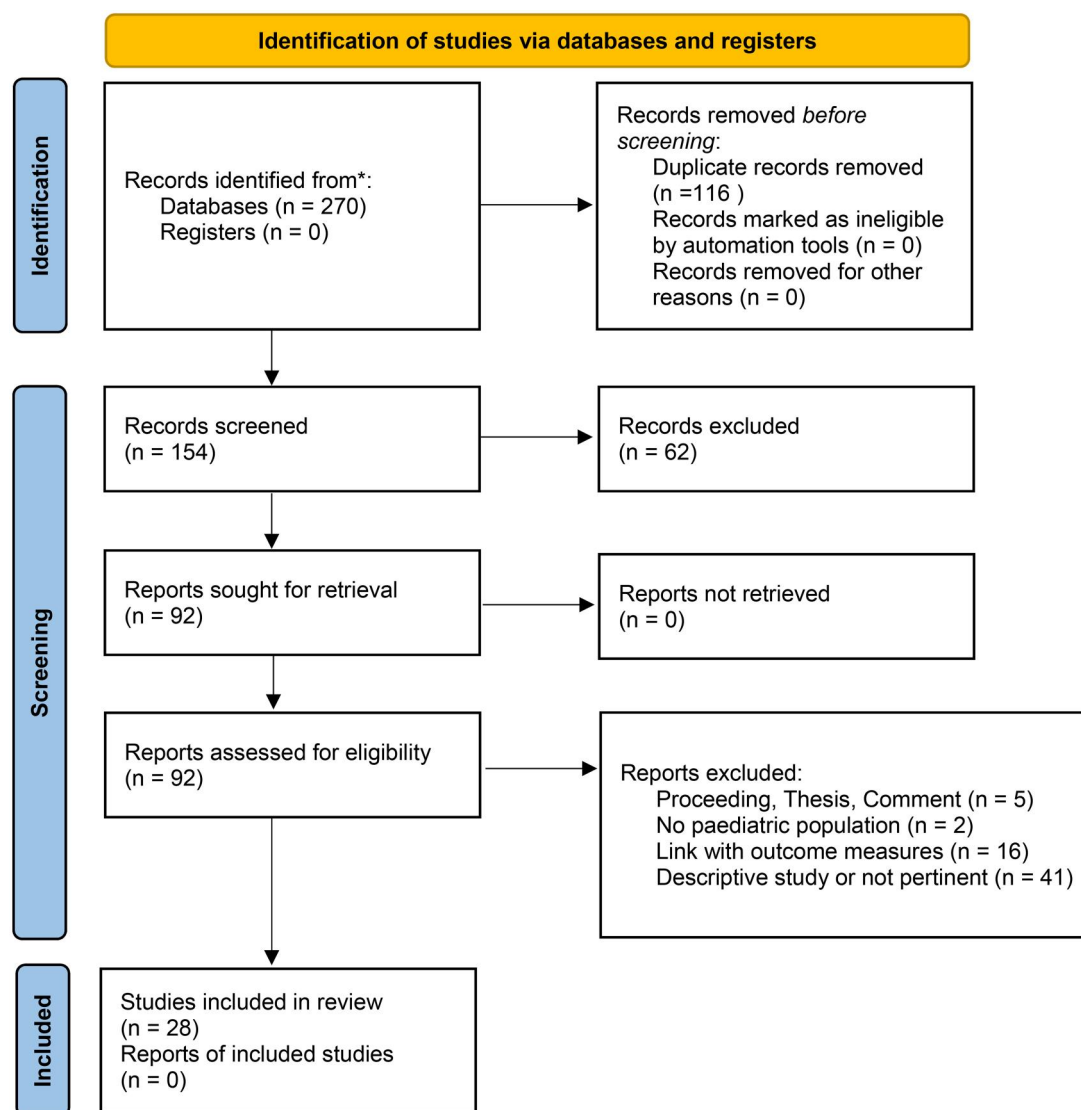


Figure 1. Flow diagram for searching and screening process.

include in the systematic review. Articles' information was then categorized by authors, year of publication, study design, health condition, methodology, domains, and main findings.

Results

Study selection

Search ended on 31 January 2022. Research on MEDLINE, CINAHL, SCOPUS, Web of Science, PEDro, and OT Seeker databases identified 270 articles. One hundred and sixteen articles appeared in more than one, and were eliminated as duplicates. One hundred and fifty-four articles were analyzed on reading the title and abstract, and 62 were excluded. Sixty-four of 92 remaining articles were excluded after reading the full-text, since many concerned linking with outcome measures or not pertinent with the objectives of the present systematic review. At the end, 28 research papers were included for qualitative synthesis. The selection process is reported in the flowchart (Figure 1), according to the PRISMA guidelines for reporting systematic reviews and meta-analyses [16,18].

Study characteristics

For each included study, the following data were obtained: author name(s) and year of publication, country of study/application, health condition, methodology, population, ICF domains (body functions, body structures, activity and participation, environmental factors), and main findings. Data are summarized in Table 1.

Country of study/application

ICF-CY Core Sets have been developed worldwide. Seventeen studies [19–22,25–31,34,35,38,40,42,45] involved international panel for determining ICF-CY Core set, while five were developed in WHO American Regions (two Canada, one USA, one Argentina, and one Brazil) [23,24,36,41,46], four in WHO Western Pacific Regions (one China, three Taiwan) [32,33,39,43], and two in WHO European Regions (one Germany, one Turkey) [37,44].

Methodology of the studies

Different methodological approaches were used to inform ICF-CY Core Set. The majority of papers used Cieza methodology,

Table 1. Data extraction table.

Study	Nationality	Health condition	Methodology	Body functions	Body structures	Activity and participation	Environmental factors	Main findings
Bölte et al. [19]	International	ADHD	Cieza methodology	Comprehensive: 8; 0–5 years: 8; 6–16 years: 8; >16 years: 7		Comprehensive: 35; 0–5 years: 19; 6–16 years: 24; >16 years: 24	Comprehensive: 29; 0–5 years: 20; 6–16 years: 23; >16 years: 21	Authors developed both comprehensive (92 categories) and age-specific brief core set for ADHD population
Bölte et al. [20]	International	ASD	Cieza methodology	Comprehensive: 20; 0–5 years: 19; 6–16 years: 18; >16 years: 18	Comprehensive: 1	Comprehensive: 59; 0–5 years: 29; 6–16 years: 36; >16 years: 34	Comprehensive: 31; 0–5 years: 25; 6–16 years: 27; >16 years: 27	Authors developed both comprehensive (111 categories) and age-specific brief core set for ASD population
Bölte et al. [21]	International	ADHD	Cieza methodology	N/A	N/A	N/A	N/A	Authors describe the methodology for ICF-CY Core Set in ADHD population
Bölte et al. [22]	International	ASD	Cieza methodology	N/A	N/A	N/A	N/A	Authors describe the methodology for ICF-CY Core Set in ASD population
Corrêa et al. [23]	Brazil	DiGeorge syndrome (22q11.2 deletion syndrome)	Delphi	28	11	70	36	Delphi method allowed to identify 145 ICF-CY categories for DiGeorge syndrome for Brazilian context
Conway et al. [24]	USA	Duchenne and Becker muscular dystrophies	Cieza methodology	23	N/A	N/A	N/A	Authors investigated only body function domain of the ICF-CY, identifying 23 categories.
de Schipper et al. [21,22]	International	ADHD	Comprehensive scoping review	31	–	32	5	The comprehensive scoping review allowed to identify 68 ICF-CY categories for ADHD population
de Schipper et al. [25–27]	International	ASD	Comprehensive scoping review	28	–	63	8	The comprehensive scoping review allowed to identify 99 ICF-CY categories for ASD population
de Schipper et al. [25–27]	International	ADHD	Expert survey	30	3	30	20	The expert survey allowed to identify 83 ICF-CY categories for ADHD population
Duijnisveld et al. [28]	International	Obstetric brachial plexus injury	Cieza methodology	N/A	N/A	N/A	N/A	Authors describe the methodology for ICF-CY Core Set in OBPI population
Faulks et al. [29]	International	Oral health	Preliminary validation study: using ICF-CY Oral Health Checklist trained investigators interviewed primary caregiver or using clinical record data	43	23	37	25	The methodology allowed to identify 128 ICF-CY categories for oral health in general pediatric population

(continued)

Table 1. Continued.

Study	Nationality	Health condition	Methodology	Body functions	Body structures	Activity and participation	Environmental factors	Main findings
Faulks et al. [30]	International	Oral health	Delphi	24	15	24	23	Delphi method allowed to identify 86 ICF-CY categories for oral health in general pediatric population
Güeita-Rodríguez et al. [31]	International	Neurological conditions and specific aquatic therapy context	Cieza methodology	Comprehensive: 26 Common brief: 6; 0–5 years: 10; 6–13 years: 14; 14–18 years: 12	Comprehensive: 8; Common brief: 1; 0–5 years: 1; 6–13 years: 1; 14–18 years: 1	Comprehensive: 27; Common brief: 6; 0–5 years: 7; 6–13 years: 7; 14–18 years: 6	Comprehensive: 3; Common brief: 0; 0–5 years: 0; 6–13 years: 0; 14–18 years: 0	Authors developed both comprehensive (64 categories) and age-specific brief core set for pediatric population with neurological condition in the specific aquatic context
Liao et al. [32]	Taiwan	CP	Matching national data set of FUNDES-Child with Comprehensive, Children and Youth CP Core Sets	N/A	N/A	34 codes for comprehensive, 10 for children and 9 for youth	N/A	Matching national data with previous studies on ICF-CY Core Set, authors identified 34 categories for children with CP in the specific Taiwanese context.
Lin et al. [33]	Taiwan	Burn injuries	Delphi	19	5	37	7	This ICF core set provides a multidimensional framework for the evaluation of functional health in patients with sequelae of burns. Effective rehabilitation strategies for patients after burns could be designed on the basis of this ICF Core Set.
Mahdi et al. [34]	International	ADHD	Focus groups plus individual interviews	23	2	32	25	The focus group provide identification of 82 categories for ICF CY Core
Mahdi et al. [35]	International	ASD	Focus groups plus individual interviews	33	3	45	29	Set for children with ADHD The focus group provide identification of 110 categories for ICF CY Core
Napoli et al. [36]	Argentina	ASD	Based on ICF Core Set on ASD, healthcare professionals and families selected significant codes for Argentina context	10	N/A	15	7	Set for children with ASD Authors developed a specific ICF Core Set (TEA-CIFunctional) incorporating the most relevant ICF categories for Argentina cultural and pediatric setting
Neumann and Romonath [37]	Germany	Cleft lip and palate	Cieza methodology	17	9	29	25	Authors identified 80 ICF CY categories for children with cleft and lip palate disorders
Pan et al. [38]	International	Children with early delay and disabilities	Delphi	29	10	28	15	A core set of 82 ICF-CY categories was developed to describe functioning of infants younger than three years of age with developmental disabilities

(continued)

Table 1. Continued.

Study	Nationality	Health condition	Methodology	Body functions	Body structures	Activity and participation	Environmental factors	Main findings
Qiu et al. [39]	China	CP	Psychometric study	8	1	8	8	Moderate to excellent reliability; good internal consistency and high inverse correlation with PEDI
Schiariti et al. [40,41]	Canada	CP	Comparative analysis	SR: 123; expert survey: 74; qualitative study: 30; clinical study: 42	SR: 8; expert survey: 65; qualitative study: 17; clinical study: 14	SR: 169; expert survey: 105; qualitative study: 72; clinical study: 48	SR: 36; expert survey: 70; qualitative study: 56; clinical study: 25	This study highlights the need to consider all relevant perspectives when describing the functional profile of CY with CP
Schiariti et al. [41,45]	International	CP	Cieza methodology	Comprehensive: 34; common brief: 8; 0–5 years: 9; 6–13: 10; 14–18 years: 10	Comprehensive: 7; common brief: 1; 0–5 years: 1; 6–13: 1; 14–18 years: 1	Comprehensive: 58; common brief: 8; 0–5 years: 11; 6–13: 13; 14–18 years: 15	Comprehensive: 36; common brief: 8; 0–5 years: 10; 6–13: 11; 14–18 years: 11	Both comprehensive and brief core set were developed for children with CP for each ICD domains.
Schiariti et al. [42]	International	Cerebral palsy, ADHD, AUTISM	Comparative content analysis	Representation: CP 25.5%; ASD: 18%; ADHD: 12%	Representation: CP 6%; ASD: 1%; ADHD: 0%	Representation: CP 41.5%; ASD: 47.5%; ADHD: 53%	Representation: CP 27%; ASD: 28%; ADHD: 40.5%	ICF Core Sets for CP, ASD, and ADHD capture both common but also unique functional information, showing the importance of creating condition-specific, ICF-based tools to build functional profiles of individuals with childhood-onset disabilities.
Schiariti et al. [40]	International	CP	Expert survey	<6 years: 10 >6 years: 8	<6 years: 7 >6 years: 6	<6 years: 9 >6 years: 7	<6 years: 8 >6 years: 9	The expert survey allowed to identify 39 categories for children under 6 years, and 30 for children
Schiariti et al. [46]	Canada	CP	Preliminary validation study based on chart review of clinical assessment	14	1	13	11	Reviewing chart and clinical assessment allowed to identify 39 ICF-CY categories for CP
Teng et al. [43]	Taiwan	General population with disabilities	Delphi	32	11	N/A	8	population in Canada A ICF core set was developed for body structure and functions, and environmental factors, while for Activity and Participation authors use Functioning Scale of Disability Evaluation System (FUNDES) Child version
Yarar et al. [44]	Turkey	Low vision	Not described	13	3	36	12	The findings indicate that the raters showed strong agreement in terms of the ICF core set used in this study

Table 2. Synthesis of the ICF-CY Core Sets for health conditions.

Cerebral palsy
Attention-deficit/hyperactivity disorder
Autism spectrum disorder
Oral health
General pediatric population
Early delay of disabilities
Neurological condition doing aquatic therapy
Cleft lip palate
Burn injuries
Di George Syndrome
Duchenne and Becker muscular dystrophy
Low Vision Disease

consisting in three different phases. The first phase in the process is collecting the evidence, consisting in four preparatory studies that capture different perspectives: an empirical multicenter study (clinical perspective), an expert survey (health professionals' perspective), a systematic literature review (research perspective), and qualitative study (perspective of persons with a health condition). In phase two, the resulting set of "candidate" ICF categories is provided to the experts and health professionals who participate in an international consensus conference during which they decide on the ICF categories to be included in the respective ICF Core set. The final phase in the process involves implementing the first version of the ICF Core set. Cieza methodology, and each phase, was used for attention-deficit/hyperactivity disorder (ADHD) [19,21,25,27,34], autism spectrum disorder (ASD) [20,22,26,35,36], cerebral palsy (CP) [40,41,45,46], children neurological condition doing aquatic therapy, cleft lip and palate. Three conceptual papers describing Cieza methodology were found for ADHD, ASD, and obstetric brachial plexus injury. Five studies [23,30,33,38,43] used a Delphi method, a process used to arrive at a group opinion or decision by surveying a panel of experts. Three studies [29,32] identified ICF-CY Core Set through experts or linking/matching information with clinical record data and/or with surveillance data. Paper on low vision did not describe in depth methodology for the development of ICF-CY-Core Set [44]. At the end, two studies [41,42] performed comparative content and methodological analysis to inform ICF Core Set.

Health condition and ICF-CY Core Set

The majority of studies investigate ICF-CY Core Set for CP with six studies [32,36,39,40,45,46], and ASD [20,21,26,35] and ADHD with five studies each [19,21,25,27,34]. Furthermore, one study performed a comparative analysis between CP, ASD, and ADHD [42]. Two studies defined ICF-CY Core Set for oral health [29,30] and three were created for a non-specific health condition, namely general pediatric population [43], children with early delay of disabilities [38] and children with neurological condition doing aquatic therapy [31]. At the end, six studies defined ICF-CY Core Set for specific population, namely cleft lip palate [37], burns injuries [33], DiGeorge Syndrome [23], Duchenne and Becker muscular dystrophy [24], and low vision disease [44]. For obstetric brachial plexus injury [28], only the methodological approach was described. Results are summarized in Table 2.

For ADHD, ASD, CP and children with neurological condition doing aquatic therapy, authors developed both comprehensive ICF-CY Core Set and Brief ICF-CY Core Set specific per age. In particular, ADHD and ASD defined specific core set for children aged 0–5 years, 6–16 years, and >16 years, while for CP and CNACT authors defined specific core sets for the following range: 0–5 years, 6–13 years, and 14–18 years.

Discussion

The ICF-CY was introduced in 2007 by the WHO and this year marks the 15th anniversary since it was launched. The present study explored the use of ICF-CY core set, internationally and identified 12 ICF-CY Core Set.

The ICF framework produced a systematic change for approaching health and disability. ICF-based approach produced a paradigm shift in healthcare models and is continuing to force a radical change in treatment and rehabilitation approaches, as well as in outcomes measurement. For instance, in Canada is proposing an ICF-informed practice model supplemented by other frameworks to facilitate interprofessional collaborative care within primary health care [47]. Furthermore, the ICF approach stimulated the whole scientific community to investigate which outcome measures can capture different ICF domains for specific health conditions [48–51]. The ICF-CY can be seen as an interactive system providing building blocks to study different aspects of child functioning in various everyday contexts and the complex relationships between functioning and contextual factors [6]. The coding system of the classification provides an opportunity to identify content and/or compare data in for example text or measures by linking information or items to components, chapters, and categories in the comprehensive classification [52,53]. The domains and classification codes of the ICF-CY can be used in collaboration within and between professional groups to jointly assess influential factors of child functioning and learning [54] have shown that professionals in child habilitation find the content in ICF-CY useful and that it is a logically coherent model. The professionals tend to find it useful for documenting children's functioning, and that the use of the ICF-CY enhanced a focus on child participation and expanded their perspectives [55]. The development of ICF-CY originates from the need to describe the functioning of children and youth in correspondence with ICF. The ICF-CY offers especially more extended points of departure and greater detail for a better description of the growth and development of children and youth. Differences with ICF took the form of modifying or expanding descriptions, assigning new content to unused codes, modifying inclusion and exclusion criteria, and expanding qualifiers to include developmental aspects. ICF-CY also contains a classification of external factors, the immediate and wider environment of a child. ICF-CY is especially extended with learning and playing aspects and the developmental process.

However, the application of ICF in clinical practice may have some difficulty, for instance, poor inter-rater reliability and regard to patients' complexity [56]. For clinical use, the comprehensiveness of the ICF-CY is a challenge. Therefore, for both ICF and ICF-CY comprehensive and brief ICF-CY Core set were developed. Reduced sets of categories have been defined as standard minimum content areas to be used for specific purposes: Brief ICF Core Sets include 10–20 categories to be used for clinical studies or population surveys whereas Comprehensive ICF Core Sets include approximately 100 categories aiming to guide multidisciplinary assessments [57].

The present study finds 12 ICF-CY Core Set for specific health conditions. Duijnisveld et al.'s study [28] only reported the methodology to use for developing ICF-CY Core Set in brachial plexus injuries, while Conway et al.'s study on Duchenne and Becker muscular dystrophies [24] identified specific categories only for body functions domain (23 categories). The rest of included studies identified specific categories for each domain of the ICF-CY, namely body functions and structures, activity and participation and environmental factors.

The most widely used methodology to inform ICF-CY Core Set was those described by Cieza et al. [10,58,59]. However, it is important point out further methodological approach resulting from the systematic review. Napoli et al. [36] developed a specific ASD Core Set (TEA-CIFunctiona) incorporating the most relevant ICF categories for the Argentinian context based on previous research [20]. Similarly, Liao et al. [32] developed specific CP Core Set for Taiwanese children matching national surveillance data with previous ICF Core Set for CP population. These studies highlight the importance to verify the feasibility and to adapt ICF Core Set for specific context and countries. In fact, if functioning, health and disability are the results of biological, psychological, and environmental factors, also the use of Core Set may vary depending on culture, society, and country. Furthermore, the importance of methodological approach is well described in Schiariti and Mässe [41] who report differences in analyzing functional profile of children with CP depending of perspective of healthcare professionals, children and caregivers or clinical studies. Authors strength the need to consider all relevant aspects when describing functional profile of a specific health condition and when researchers approach to the development of ICF-CY Core Set.

With respect to the only other review on the development of ICF Core Set for adults [14], we registered differences in quantity of research products. Basically, we included 28 research papers while for adulthood in 2012 were retrieved 116 research papers. Furthermore, we find only 12 ICF Core Set for children and youth, while for adults were find more than 100 comprehensive core sets. Why ICF-CY Core Set seem to be under-utilized? The answer is probably not to be found in this review, not least because we set different objectives. However, a few considerations can be made. First, there is probably a difficulty in using ICF-CY and lack of training. Globally, the ease of ICF-CY usage was classified as low to moderate, highlighting the need for training and routinization of the new practices [60]. Although the explicit positive impact on using ICF-CY [61], professionals with different background highlight the need of support or change in different area, namely (a) the need of specialized training, (b) greater collaboration mechanisms between schools and health and social services, and (c) the development of assessment measures consistent with ICF-CY framework. Moreover, analyzing the publications included in our systematic review we can see that 50% of the publications were produced by the same group of researchers, and the same have then collaborated in some papers together with other groups. Therefore, a massive training program to disseminate methodological approach to inform ICF-CY Core Set and best practices is urgently recommended. Moreover, as described by Cieza et al. [10,58], the proper development of ICF-Core Sets required several phases that take more time, at least three years. Therefore, the study and research process require substantial financial support. Not surprisingly, the most comprehensive Core Sets have been developed in high income countries and through research grants. An international effort to strength collaboration between research centers, academics of both high- and low/middle-income countries is required.

The present systematic review has some limitations. First, we reviewed studies from various countries, and we do not impose any language restriction; for those languages in which authors have no good command (e.g., Farsi, Chinese, and Korean) we involved professional translators with no specific health background. In addition, the methodological quality of the studies could not be assessed. We noted that most studies used the

methodology described Cieza et al., but we could not perform comparisons between different studies in different settings.

In conclusion, the present study found a relatively small amount of ICF-CY Core Set and this probably represents the main barrier in using ICF framework in developmental age. Further effort at international level should be undertaken to share operational methodologies, support virtuous research processes and disseminate good practices that are consistent with the bio-psycho-social vision of the ICF.

Disclosure statement

The authors report there are no competing interests to declare.

Funding

The author(s) reported there is no funding associated with the work featured in this article.

ORCID

Marco Tofani  <http://orcid.org/0000-0003-2071-4513>
 Martina Mustari  <http://orcid.org/0000-0002-9749-6318>
 Emanuela Tiozzo  <http://orcid.org/0000-0002-8815-5626>
 Immacolata Dall'Oglio  <http://orcid.org/0000-0002-2398-2014>
 Orsola Gawronsky  <http://orcid.org/0000-0001-8686-5897>
 Enrico Castelli  <http://orcid.org/0000-0003-1685-8936>

References

- [1] World Health Organization. The ICF: an overview. World Health Organization; Geneva 2001.
- [2] World Health Organization. ICD-10: International Statistical Classification of Diseases and Related Health Problems: tenth revision. 2nd ed. Geneva, World Health Organization; 2004.
- [3] Tofani M, Berardi A, Iorio S, et al. Exploring global needs of migrants with disability within a community-based inclusive development perspective. *Ann Ist Super Sanita*. 2022; 58(2):124–130.
- [4] World Health Organization. International Classification of Functioning, Disability and Health. Geneva: WHO; 2001.
- [5] Stucki G, Grimby G. Applying the ICF in medicine. *J Rehabil Med*. 2004;36:5–6.
- [6] World Health Organization. International Classification of Functioning, Disability and Health: children and youth version: ICF-CY. Geneva: World Health Organization; 2007.
- [7] Kostanjsek N. Use of the International Classification of Functioning, Disability and Health (ICF) as a conceptual framework and common language for disability statistics and health information systems. *BMC Public Health*. 2011; 11(Suppl. 4):S3–S6.
- [8] Stucki G, Ewert T, Cieza A. Value and application of the ICF in rehabilitation medicine. *Disabil Rehabil*. 2002;24(17): 932–938.
- [9] Cieza A, Brockow T, Ewert T, et al. Linking health-status measurements to the International Classification of Functioning, Disability and Health. *J Rehabil Med*. 2002; 34(5):205–210.
- [10] Cieza A, Geyh S, Chatterji S, et al. ICF linking rules: an update based on lessons learned. *J Rehabil Med*. 2005; 37(4):212–218.

- [11] Üstün TB, Chatterji S, Bickenbach J, et al. The International Classification of Functioning, Disability and Health: a new tool for understanding disability and health. *Disabil Rehabil.* 2003;25(11–12):565–571.
- [12] Danermark B, Cieza A, Gangé JP, et al. International Classification of Functioning, Disability, and Health Core Sets for hearing loss: a discussion paper and invitation. *Int J Audiol.* 2010;49(4):256–262.
- [13] Cerniauskaite M, Quintas R, Boldt C, et al. Systematic literature review on ICF from 2001 to 2009: its use, implementation and operationalisation. *Disabil Rehabil.* 2011;33(4):281–309.
- [14] Yen TH, Liou TH, Chang KH, et al. Systematic review of ICF core set from 2001 to 2012. *Disabil Rehabil.* 2014;36(3):177–184.
- [15] Moretti M, Alves I, Maxwell G. A systematic literature review of the situation of the International Classification of Functioning, Disability, and Health and the International Classification of Functioning, Disability, and Healthy children and youth version in education: a useful tool or a flight of fancy? *Am J Phys Med Rehabil.* 2012;91:S103–S117.
- [16] Page MJ, Moher D, Bossuyt PM, et al. PRISMA 2020 explanation and elaboration: updated guidance and exemplars for reporting systematic reviews. *BMJ.* 2021;372:n160.
- [17] Higgins JPT, Sally G, editors. *Cochrane handbook for systematic reviews of interventions*. Version 5.1.0. The Cochrane Collaboration; Oxford 2011.
- [18] Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ.* 2021;372:n71.
- [19] Bölte S, Mahdi S, Coghill D, et al. Standardised assessment of functioning in ADHD: consensus on the ICF Core Sets for ADHD. *Eur Child Adolesc Psychiatry.* 2018;27(10):1261–1281.
- [20] 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 International Classification of Functioning, Disability and Health Core Sets. *Autism.* 2019;23(2):449–467.
- [21] 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.* 2014;23(12):1139–1148.
- [22] Bölte S, de Schipper E, Robison JE, et al. Classification of functioning and impairment: the development of ICF Core Sets for autism spectrum disorder. *Autism Res.* 2014;7(1):167–172.
- [23] Corrêa APC, Ribeiro CTM, Horovitz DDG, et al. Identification of relevant International Classification of Functioning Disability and Health (ICF) categories in patients with 22q11.2 deletion syndrome: a Delphi exercise. *Codas.* 2020;32(6):e20190158.
- [24] Conway KM, Ciafaloni E, Matthews D, et al. Application of the International Classification of Functioning, Disability and Health system to symptoms of the Duchenne and Becker muscular dystrophies. *Disabil Rehabil.* 2018;40(15):1773–1780.
- [25] de Schipper E, Mahdi S, Coghill D, et al. Towards an ICF core set for ADHD: a worldwide expert survey on ability and disability. *Eur Child Adolesc Psychiatry.* 2015;24(12):1509–1521.
- [26] de Schipper E, Lundequist A, Coghill D, et al. Ability and disability in autism spectrum disorder: a systematic literature review employing the International Classification of Functioning, Disability and Health-Children and youth version. *Autism Res.* 2015;8(6):782–794.
- [27] de Schipper E, Lundequist A, Willeus AL, et al. A comprehensive scoping review of ability and disability in ADHD using the International Classification of Functioning, Disability and Health-Children and youth version (ICF-CY). *Eur Child Adolesc Psychiatry.* 2015;24(8):859–872.
- [28] Duijnisveld BJ, Saraç Ç, Malessy MJA, et al. Developing core sets for patients with obstetric brachial plexus injury based on the International Classification of Functioning, Disability and Health. *Bone Joint Res.* 2013;2(6):116–121.
- [29] Faulks D, Norderyd J, Molina G, et al. Using the International Classification of Functioning, Disability and Health (ICF) to describe children referred to special care or paediatric dental services. *PLOS One.* 2013;8(4):e61993.
- [30] Faulks D, Molina G, Eschevins C, et al. Child oral health from the professional perspective – a global ICF-CY survey. *Int J Paediatr Dent.* 2016;26(4):266–280.
- [31] Güeita-Rodríguez J, García-Muro F, Rodríguez-Fernández ÁL, et al. Preliminary aquatic physical therapy core sets for children and youth with neurological disorders: a consensus process. *Pediatr Phys Ther.* 2019;31(3):272–278.
- [32] Liao HF, Hwang AW, Schiariti V, et al. Validating the ICF Core Set for cerebral palsy using a national disability sample in Taiwan. *Disabil Rehabil.* 2020;42(5):642–650.
- [33] Lin YR, Wang JY, Chang SC, et al. Developing a Delphi-based comprehensive core set from the International Classification of Functioning, Disability, and Health framework for the rehabilitation of patients with burn injuries. *Int J Environ Res Public Health.* 2021;18(8):3970.
- [34] Mahdi S, Viljoen M, Massuti R, et al. An international qualitative study of ability and disability in ADHD using the WHO-ICF framework. *Eur Child Adolesc Psychiatry.* 2017;26(10):1219–1231.
- [35] Mahdi S, Viljoen M, Yee T, et al. An international qualitative study of functioning in autism spectrum disorder using the World Health Organization International Classification of Functioning, Disability and Health framework. *Autism Res.* 2018;11(3):463–475.
- [36] Napoli SB, Vitale MP, Cafiero PJ, et al. Developing a culturally sensitive ICF-based tool to describe functioning of children with autism spectrum disorder: TEA-CIFunciona version 1.0 pilot study. *Int J Environ Res Public Health.* 2021;18(7):3720.
- [37] Neumann S, Romonath R. Application of the International Classification of Functioning, Disability, and Health-Children and Youth version (ICF-CY) to cleft lip and palate. *Cleft Palate Craniofac J.* 2012;49(3):325–346.
- [38] Pan YL, Hwang AW, Simeonsson RJ, et al. ICF-CY code set for infants with early delay and disabilities (EDD code set) for interdisciplinary assessment: a global experts survey. *Disabil Rehabil.* 2015;37(12):1044–1054.
- [39] Qiu X, Jiang Z, Meng J. Preliminary clinical application of brief common ICF Core Set for children and youth with cerebral palsy. *Chin J Rehabil Med.* 2016;31.
- [40] Schiariti V, Mâsse 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(5):582–591.

- [41] Schiariti V, Mâsse LC. Identifying relevant areas of functioning in children and youth with cerebral palsy using the ICF-CY coding system: from whose perspective? *Eur J Paediatr Neurol.* **2014**;18(5):609–617.
- [42] 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(9):933–941.
- [43] Teng SW, Yen CF, Liao HF, et al. Evolution of system for disability assessment based on the International Classification of Functioning, Disability, and Health: a Taiwanese study. *J Formos Med Assoc.* **2013**;112(11):691–698.
- [44] Yazar F, Cavlak U, Başakcı Çalık B. Applying the International Classification of Functioning, Disability, and Health in Children with Low Vision: differences between raters. *Turk J Med Sci.* **2016**;46(6):1694–1699.
- [45] Schiariti V, Selb M, Cieza A, et al. 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(2):149–158.
- [46] Schiariti V, Mâsse LC. Relevant areas of functioning in children with cerebral palsy based on the International Classification of Functioning, Disability and Health coding system: a clinical perspective. *J Child Neurol.* **2015**;30(2):216–222.
- [47] Dufour SP, Lucy SD. Situating primary health care within the International Classification of Functioning, Disability and Health: enabling the Canadian Family Health Team Initiative. *J Interprof Care.* **2010**;24(6):666–677.
- [48] Chien CW, Rodger S, Copley J, et al. Comparative content review of children's participation measures using the International Classification of Functioning, Disability and Health – Children and Youth. *Arch Phys Med Rehabil.* **2014**;95(1):141–152.
- [49] Angsupaisal M, Maathuis CGB, Hadders-Algra M. Adaptive seating systems in children with severe cerebral palsy across International Classification of Functioning, Disability and Health for children and youth version domains: a systematic review. *Dev Med Child Neurol.* **2015**;57(10):919–930.
- [50] Petersson C, Simeonsson RJ, Enskar K, et al. Comparing children's self-report instruments for health-related quality of life using the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY). *Health Qual Life Outcomes.* **2013**;11:75.
- [51] Castro S, Ferreira T, Dababnah S, et al. Linking autism measures with the ICF-CY: functionality beyond the borders of diagnosis and interrater agreement issues. *Dev Neurorehabil.* **2013**;16(5):321–331.
- [52] Simeonsson RJ, Leonardi M, Lollar D, et al. Applying the International Classification of Functioning, Disability and Health (ICF) to measure childhood disability. *Disabil Rehabil.* **2003**;25(11–12):602–610.
- [53] Lee AM. Using the ICF-CY to organise characteristics of children's functioning. *Disabil Rehabil.* **2011**;33(7):605–616.
- [54] Björck-Åkesson E, Wilder J, Granlund M, et al. The International Classification of Functioning, Disability and Health and the version for children and youth as a tool in child habilitation/early childhood intervention – feasibility and usefulness as a common language and frame of reference for practice. *Disabil Rehabil.* **2010**;32(Suppl. 1):S125–S138.
- [55] Adolfsson M, Sjöman M, Björck-Åkesson E. ICF-CY as a framework for understanding child engagement in pre-school. *Front Educ.* **2018**;3.
- [56] Maini M. Problematiche applicative dell'uso dei core set ICF in ambito riabilitativo [Application problems of the use of the core set ICF in the rehabilitation area]. *G Ital Med Lav Ergon.* **2008**;30:178–184.
- [57] Adolfsson M. Applying the ICF-CY to identify everyday life situations of children and youth with disabilities; **2011** [cited 2022 Apr 4]. Available from: www.hlk.hj.se
- [58] Selb M, Escorpizo R, Kostanjsek N, et al. A guide on how to develop an International Classification of Functioning, Disability and Health Core Set. *Eur J Phys Rehabil Med.* **2022**;51:105–117.
- [59] Cieza A, Fayed N, Bickenbach J, et al. Refinements of the ICF linking rules to strengthen their potential for establishing comparability of health information. *Disabil Rehabil.* **2019**;41(5):574–583.
- [60] Sanches-Ferreira M, Silveira-Maia M, Alves S, et al. Conditions for implementing the ICF-CY in education: the experience in Portugal. *Front Educ.* **2018**;3:20.
- [61] Sanches-Ferreira M, Silveira-Maia M, Alves S. The use of the International Classification of Functioning, Disability and Health, Version for Children and Youth (ICF-CY), in Portuguese Special Education Assessment and Eligibility Procedures: the professionals' perceptions. *Eur J Spec Needs Educ.* **2014**;29(3):327–343.