

International Classification of Functioning, Disability and Health Core Sets for children and youth with cerebral palsy: a consensus meeting

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ABBREVIATIONS

ICF-CY International Classification of Functioning, Disability and Health Children and Youth version
QOL Quality of life

AIM The objective of this article is to report on the Core Sets developed for children and youth aged 0 to 18 years, with cerebral palsy (CP) based on the pediatric International Classification of Functioning, Disability and Health (ICF) by the World Health Organization (WHO).

METHOD A formal decision-making and consensus process integrating evidence gathered from preparatory studies was followed. Preparatory studies included: a systematic literature review; an international expert survey; a qualitative study of children and youth with CP and their caregivers; and a clinical study. Relevant ICF categories were identified in a formal consensus process by international experts from different backgrounds. Twenty-six international experts chosen by WHO region with expertise in CP attended the consensus meeting.

RESULTS Overall, five ICF Core Sets were developed: a Comprehensive Core Set (135 ICF categories); a Common Brief (25 ICF categories); and three age-specific Core Sets: under 6 years (31 ICF categories), from 6 to <14 years (35 ICF categories) and from 14 to 18 years (37 ICF categories).

INTERPRETATION These ICF Core Sets for children and youth with CP are the first ICF-based tools developed for this population. The ICF Core Sets for children and youth with CP can be applied in clinical practice, research, teaching and administration. The application of the ICF Core Sets to this population will standardize the functional assessments of CP worldwide.

Cerebral palsy (CP) is the leading cause of severe physical disability in childhood with an estimated prevalence of 2 to 2.5 per 1000 children in developed countries.¹⁻⁴ CP is a complex disorder in which the motor disorders are often accompanied by disturbances of sensation, perception, cognition, communication and behavior, as well as seizure disorders.⁵ CP is a life-long disorder that has implications for the individual's schooling and vocational development. As such, individuals with CP rely on many health and educational services. In order to improve their functioning, quality of life (QOL) and educational outcomes, we must first understand the functional abilities of individuals living with CP and the challenges they face in performing everyday activities.

'Functioning' is an umbrella term to describe what a person with a health condition does or is able to do in everyday life. As used by the World Health Organization (WHO), it is the foundation of the International Classification of Functioning, Disability and Health (ICF).⁶ The ICF⁷ can serve as a useful tool to standardize the description of the functional abilities and challenges children and youth with CP have in performing everyday activities.

In recent decades, functional abilities including social participation have been increasingly the focus of study in children and youth with CP.⁸⁻¹⁹ The research community highlights the importance of addressing functional goals in the treatment of children and youth with CP. What remains lacking is how to describe systematically the functional profile of children and youth with CP.

The ICF offers a framework for understanding functioning and disability comprehensively from a bio-psychosocial perspective.⁷ This bio-psychosocial model of functioning and disability includes four components: (1) body functions and structures; (2) activities and participation; (3) personal; and (4) environmental factors.⁷

The ICF structures health and health-related domains into a hierarchy starting with components as mentioned above, then chapters, followed by categories. An ICF category is represented by an alphanumeric code. This alphanumeric code starts with the letters b, s, d or e and each letter denotes one of the components of the ICF (body functions, body structures, activities and participation, and environmental factors respectively). The letter is followed

by a numeric code of which the first digit denotes the chapter. To provide greater specificity, second (two digits), third and fourth level (one digit each) codes are provided⁷ (Fig. S1, online supporting information).

The paediatric version of the ICF (ICF-CY)²⁰ records the characteristics of the developing child and the influence of his or her surrounding environment. The project outlined in this article employed the ICF-CY. The ICF-CY consists of 1685 categories.²⁰ This comprehensiveness limits the utility of the ICF-CY (referred to as 'ICF' going forward in this article) in daily clinical practice and research activities. Moreover, to facilitate its application, the strategy for using the ICF must be tailored to the needs of different users. This need for individualization is the primary motivation behind the development of the ICF Core Sets.⁶ 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. Each ICF Core Set development project includes the development of a Comprehensive and 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. 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.⁶ ICF Core Sets can be used to help understand clients' needs, to assess and report client functioning in different settings, and in intervention planning.^{6,21,22}

At present, there are no ICF Core Sets for children and youth. Our research team, in collaboration with the ICF Research Branch of the WHO German Collaborating Centre for the Family of International Classifications, has led the development of the ICF Core Sets for children and youth with CP. The overall purpose of the ICF Core Sets for children and youth with CP is to identify which ICF categories best represent the functional profile of this population with CP aged 0 to 18 years, covering all types of CP and at all functional levels. The application of ICF Core Sets will encourage professionals to consider beyond the physical abilities of the child while examining the influence of the personal and environmental attributes on functioning. The categories of the ICF Core Sets can be used as a 'common language' in regular assessments of a child or adolescent with CP.

The objective of this article is to report on the final phase of the development of the ICF Core Sets for children and youth with CP: the international consensus meeting. The specific objectives of the meeting were to present the evidence collected in the preparatory phase of the project to the participating experts, and to select the most relevant ICF categories to be included in the Comprehen-

What this paper adds

- It describes the first ICF-based tools for children and youth with CP.
- It integrates international, multidisciplinary perspectives from experts in the field of childhood disability.
- It standardizes functional assessments of children and youth with CP worldwide.
- It facilitates the application of the ICF in clinical and research settings.

sive and Brief ICF Core Sets for children and youth with CP.

METHOD

The development of ICF Core Sets followed the methodology endorsed by WHO⁶ which integrates evidence from four different studies (preparatory phase): (1) a systematic review of the literature to describe the relevant aspects of functioning included in studies with children and youth with CP;²³ (2) surveying international CP experts to identify the most relevant areas of functioning to assess in this population from the professionals' perspective;²⁴ (3) a qualitative study involving interviews of children and adolescents with CP and their caregivers to identify strengths and limitations in day-to-day activities in this population;²⁵ and (4) a clinical study of clinical encounters to identify the most relevant areas of functioning covered in interdisciplinary assessments.²⁶

After these studies are completed, international experts from different backgrounds in the field were invited to a consensus meeting to review the findings of the four studies and achieve consensus on the ICF categories to be included in the final ICF Core Sets (Fig. S2, online supporting information).

In this article we describe the results of the ICF consensus meeting which took place in Vancouver, Canada in June 2013.

Recruitment of conference participants

Experts meeting the following inclusion criteria were invited to participate in this consensus meeting: (1) a professional background in childhood disability; (2) at least 5 years of experience in working with children and youth with CP; and (3) focus of practice was primarily in paediatric physical disabilities. Experts were required to be fluent in English.

A stratified random sample of experts, representing each profession and each WHO region, was drawn from a pool of experts²⁴ with the goal of ensuring representation across professions and regions (Fig. 1). Additionally, as we regarded parents of children and adolescents with CP as 'experts', two parents were invited to participate in this meeting.

Expert participants

Overall, 29 experts accepted the invitation, of which three declined for personal reasons. Participants represented all the WHO regions, with diverse professional backgrounds (e.g. developmental paediatrics, paediatric neurology,

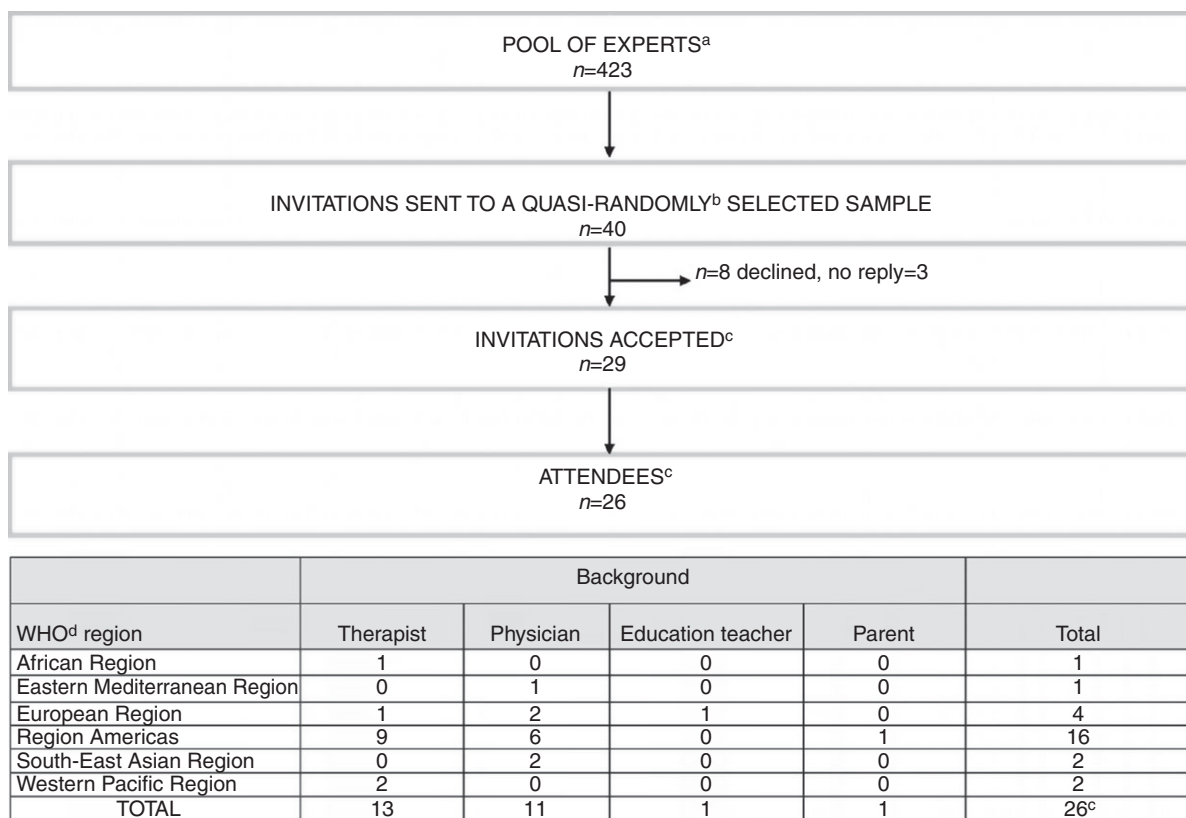


Figure 1: Recruitment process and participants' characteristics by profession and World Health Organization health regions. ^aA complete description of the pool of experts is available.²⁴ ^bRandom sample taken from the WHO regions: Americas, African, Eastern Mediterranean, South-East Asian, Western Pacific and European regions. Direct invitations were sent to participants in British Columbia, Canada. In addition, direct invitations were sent to staff members at Sunny Hill Health Centre, Vancouver, Canada. ^cThree participants, a special education teacher from the Eastern Mediterranean Region a developmental paediatrician from the European region and a parent from the Americas region could not attend the meeting because of personal reasons. ^d WHO, World Health Organization.

paediatric orthopaedic surgery, rehabilitation medicine, occupational therapy, physical therapy, special education; Fig. 1). One parent participated in the consensus meeting. (Appendix SI, online supporting information).

Training and information exchange

Participants engaged in a condensed ICF workshop at the start of the meeting to gain understanding of the ICF. Subsequently, they examined the 497 categories identified in the preparatory phase of the project²⁷ one by one, which informed their discussions and served as the starting point for the voting process.

Iterative decision-making process

During the 3-day meeting, the experts identified the ICF Core Set categories in an iterative open decision-making process based on a pre-set list of categories resulting from the four preparatory studies²⁷ and using a specialized data analysis program to track the voting process and generate results informing the subsequent step. In previous ICF Core Set development projects, a Comprehensive and a Brief ICF Core Set were developed.^{6,21,22}

In this project to develop ICF Core Sets for children and youth with CP, four Brief ICF Core Sets were developed to reflect the developmental stages of children and youth with CP (Fig. S3, online supporting information).

The decision-making process consisted of two major parts. Part one involved selecting the ICF categories to be included in the comprehensive set in alternating working groups and plenary sessions. See Table SI (online supporting information), for the distribution of participants in the working groups. Consensus agreement among the experts was set at $\geq 75\%$ for inclusion in the Core Set. Part two involved deciding on the brief set(s). The comprehensive set should include enough categories to describe the prototypical functional profile of children and youth with CP, yet be concise enough to be practical for comprehensive, interdisciplinary assessments. Conversely, the brief set should include the fewest categories possible to serve as a minimal international standard for assessing and reporting functioning in the clinical setting and for research. There

was no pre-set required number of categories. Part one has been described in detail in previous publications.²⁸

In the second part, the participants were asked to select those categories from the comprehensive set for inclusion in the brief sets. This task was achieved through a two-round ranking exercise and a final vote. As this was the first consensus meeting on children and youth, paediatric-specific adaptations were made to the methodology. The research team and the participants agreed that the ICF Core Sets should reflect developmental stages, resulting in the decision to develop separate brief sets for children and youth below 6 years, from 6 to <14 years and from 14 to 18 years. Additionally, a common brief set was created, that comprised categories present across all three age groups. The ranking and voting procedure was repeated to develop each of the brief sets. The Common Brief ICF Core Set was developed first, with its categories included in the three age-specific sets. Next, the participants decided which additional categories were essential for inclusion in each of the age-groups (e.g. d820–Education for the school-age group).

RESULT

From the consensus meeting, five ICF Core Sets were developed.

Comprehensive ICF Core Set for children and youth with CP aged 0 to 18 years

The first milestone of the consensus meeting was the creation of the Comprehensive ICF Core Set. The experts included 135 ICF categories, 130 categories (96%) at the second level and five categories (4%) at the third level (Table I). Of the 135 categories, 58 (43%) were categories of the ICF component activities and participation, 36 (27%) environmental factors, 34 (25%) body functions and seven (5%) body structures. Table SII (online supporting information) summarizes the distribution of categories included in the ICF Core Sets by chapters.

Common Brief ICF Core Set for children and youth with CP aged 0 to 18 years

The second milestone of the consensus meeting was the creation of the Common Brief ICF Core Set, containing the minimum set of categories to describe functioning in children and youth with CP. This Core Set is applicable to children and youth with CP from birth to adolescence; as its categories are included in each age-specific Brief Core Set. The experts agreed on 25 categories (body functions $n=8$, activities and participation $n=8$, environmental factors $n=8$ and body structures $n=1$) for inclusion in the common set (Table I).

Age-specific Brief ICF Core Set for children and youth with CP

The last milestone was the development of the age-specific Brief ICF Core Sets.

Brief ICF Core Set for children with CP aged 0 to <6 years

Representing the youngest group, six categories were added to the common set. In total, 31 categories were included in the Brief ICF Core Set for children younger than 6 years (Table I).

Brief ICF Core Set for children and youth with CP aged 6 to <14 years

Similarly, reflecting the school-aged group, 10 categories were added to the common set. In total, 35 categories were included in the Brief ICF Core Set for school-aged children (Table I).

Brief ICF Core Set for youth with CP aged 14 to 18 years

Finally, for the group transitioning to young adulthood, 12 categories were added to the common set. In total, 37 categories were included in the Brief ICF Core Set for adolescent transitioning into adulthood (Table I).

During the consensus meeting, the experts strived to create concise yet accurate Core Sets, capturing the key characteristics and relevant contextual factors of children and youth with CP. Experts were challenged to prioritize when voting for each category in an attempt to keep the ICF Core Sets practical and applicable. As expected, categories related to mobility, self-care, movement-related functions, pain, seeing functions, and structures of upper and lower extremities were included almost unanimously by the experts. Categories were excluded more often based on the premise that they were not specifically for children and youth with CP. Some categories were excluded to avoid redundancy (e.g. b761–Spontaneous movements was excluded as its content was represented by other included categories). Furthermore, some categories were excluded based on very specific definitions, relevant only for a certain age group. As such, d475–Driving was excluded as it is mainly applicable to a small group of adolescents; moreover, different countries have different age requirements for driving.

DISCUSSION

This consensus meeting provided a platform whereby the group of international multidisciplinary experts was enabled to consider the evidence collected in the preparatory phase of the project, engage in discussion, and – ultimately – select the categories of the ICF Core Sets for children and youth with CP via a consensus process. This meeting produced the first paediatric ICF-based tools that will facilitate a systematic description of the functional profile of children and youth with CP. The ICF Core Sets for children and youth with CP will standardize data collection regarding functioning in this population, facilitating comparisons across studies. Rigorous, systematic data collection is essential to ensure excellence in research. For CP, this can be achieved if the ICF Core Sets are used consistently across settings and internationally.

Table I: International Classification of Functioning, Disability and Health Core Sets for children and youth with cerebral palsy (CP)

Comprehensive ICF Core Set for children and youth with CP			Brief ICF Core Sets for children and youth with CP			
0–18y n=135			Common Brief			
Code	ICF category name	Age-specific Brief Core Set				
		0–18y n=25	0–<6y n=31	≥6–<14y n=35	≥14–18y n=37	
Body structures						
	<i>s1</i>	<i>Structures of the nervous system</i>				
1	s110	Structure of brain	X	X	X	X
	<i>s3</i>	<i>Structures involved in voice and speech</i>				
2	s320	Structure of mouth				
	<i>s7</i>	<i>Structures related to movement</i>				
3	s730	Structure of upper extremity				
4	s750	Structure of lower extremity				
5	s760	Structure of trunk				
6	s7700	Bones				
7	s7703	Extra-articular ligaments, fasciae, extramuscular aponeuroses, retinacula, septa, bursae, unspecified				
Body functions						
	<i>b1</i>	<i>Mental functions</i>				
8	b117	Intellectual functions	X	X	X	X
9	b126	Temperament and personality functions				
10	b1301	Motivation			X	X
11	b134	Sleep functions	X	X	X	X
12	b140	Attention functions			X	
13	b152	Emotional functions				
14	b156	Perceptual functions				
15	b163	Basic cognitive functions				
16	b164	Higher-level cognitive functions				X
17	b167	Mental functions of language	X	X	X	X
	<i>b2</i>	<i>Sensory functions and pain</i>				
18	b210	Seeing functions	X	X	X	X
19	b2152	Functions of external muscles of the eye				
20	b230	Hearing functions		X		
21	b260	Proprioceptive function				
22	b280	Sensation of pain	X	X	X	X
	<i>b3</i>	<i>Voice and speech functions</i>				
23	b320	Articulation functions				
	<i>b4</i>	<i>Functions of the cardiovascular, haematological, immunological and respiratory systems</i>				
24	b440	Respiration functions				
25	b445	Respiratory muscle functions				
26	b4501	Transportation of airways mucus				
27	b455	Exercise tolerance functions				
	<i>b5</i>	<i>Functions of the digestive, metabolic and endocrine systems</i>				
28	b510	Ingestion functions				
29	b525	Defecation functions				
30	b530	Weight maintenance functions				
	<i>b6</i>	<i>Genitourinary and reproductive functions</i>				
31	b620	Urination functions				
	<i>b7</i>	<i>Neuromusculoskeletal and movement-related functions</i>				
32	b710	Mobility of joint functions	X	X	X	X
33	b715	Stability of joint functions				
34	b730	Muscle power functions				
35	b735	Muscle tone functions	X	X	X	X
36	b740	Muscle endurance functions				
37	b755	Involuntary movement reaction functions				
38	b760	Control of voluntary movement functions	X	X	X	X
39	b765	Involuntary movement functions				
40	b770	Gait pattern functions				
	<i>b8</i>	<i>Functions of the skin and related structures</i>				
41	b810	Protective functions of the skin				
Activities and participation						
	<i>d1</i>	<i>Learning and applying knowledge</i>				
42	d110	Watching				

Table I: Continued

Comprehensive ICF Core Set for children and youth with CP 0–18y n=135			Brief ICF Core Sets for children and youth with CP			
Code	ICF category name	Common Brief 0–18y n=25	Age-specific Brief Core Set			
			0–<6y n=31	≥6–<14y n=35	≥14–18y n=37	
43	d115	Listening				
44	d120	Other purposeful sensing				
45	d130	Copying				
46	d131	Learning through actions with objects				
47	d133	Acquiring language		X		
48	d137	Acquiring concepts				
49	d140	Learning to read				
50	d145	Learning to write				
51	d155	Acquiring skills		X		
52	d160	Focusing attention				
53	d166	Reading				
54	d170	Writing				
55	d172	Calculating				
56	d175	Solving problems			X	X
57	d177	Making decisions				
	d2	<i>General tasks and demands</i>				
58	d220	Undertaking multiple tasks				
59	d230	Carrying out daily routine			X	
60	d250	Managing one's own behaviour				X
	d3	<i>Communication</i>				
61	d310	Communicating with – receiving – spoken messages				
62	d330	Speaking				
63	d331	Pre-talking				
64	d335	Producing nonverbal messages				
65	d350	Conversation			X	
66	d360	Using communication devices and techniques				
	d4	<i>Mobility</i>				
67	d410	Changing basic body position				
68	d415	Maintaining a body position	X	X	X	X
69	d420	Transferring oneself				
70	d430	Lifting and carrying objects				
71	d435	Moving objects with lower extremities				
72	d440	Fine hand use	X	X	X	X
73	d445	Hand and arm use				
74	d450	Walking	X	X	X	X
75	d455	Moving around				
76	d460	Moving around in different locations	X	X	X	X
77	d465	Moving around using equipment				
78	d470	Using transportation				
	d5	<i>Self-care</i>				
79	d510	Washing oneself				
80	d520	Caring for body parts				
81	d530	Toileting	X	X	X	X
82	d540	Dressing				
83	d550	Eating	X	X	X	X
84	d560	Drinking				
85	d570	Looking after one's health				X
	d6	<i>Domestic life</i>				
86	d630	Preparing meals				
87	d640	Doing housework				
	d7	<i>Interpersonal interactions and relationships</i>				
88	d710	Basic interpersonal interactions	X	X	X	X
89	d720	Complex interpersonal interactions				X
90	d750	Informal social relationships				
91	d760	Family relationships	X	X	X	X
92	d770	Intimate relationships				
	d8	<i>Major life areas</i>				
93	d815	Preschool education				
94	d820	School education			X	X
95	d845	Acquiring, keeping and terminating a job				X

Table I: Continued

Comprehensive ICF Core Set for children and youth with CP			Brief ICF Core Sets for children and youth with CP			
0–18y n=135			Common Brief			
Code	ICF category name	Age-specific Brief Core Set				
		0–18y n=25	0–<6y n=31	≥6–<14y n=35	≥14–18y n=37	
96	d860	Basic economic transactions				
97	d880	Engagement in play		X		
	d9	<i>Community, social and civic life</i>				
98	d910	Community life				
99	d920	Recreation and leisure			X	X
Environmental factors						
	e1	<i>Products and technology</i>				
100	e110	Products or substances for personal consumption				
101	e115	Products and technology for personal use in daily living	X	X	X	X
102	e120	Products and technology for personal indoor and outdoor mobility and transportation	X	X	X	X
103	e125	Products and technology for communication	X	X	X	X
104	e130	Products and technology for education			X	
105	e140	Products and technology for culture, recreation and sport			X	
106	e150	Design, construction and building products and technology of buildings for public use	X	X	X	X
107	e155	Design, construction and building products and technology of buildings for private use				
108	e160	Products and technology of land development				
109	e165	Assets				
	e3	<i>Support and relationships</i>				
110	e310	Immediate family	X	X	X	X
111	e315	Extended family				
112	e320	Friends	X	X	X	X
113	e325	Acquaintances, peers, colleagues, neighbours and community members				
114	e330	People in positions of authority				
115	e340	Personal care providers and personal assistants				
116	e355	Health professionals		X		
	e4	<i>Attitudes</i>				
117	e410	Individual attitudes of immediate family members		X		
118	e415	Individual attitudes of extended family members				
119	e420	Individual attitudes of friends				X
120	e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members				
121	e430	Individual attitudes of people in positions of authority				
122	e440	Individual attitudes of personal care providers and personal assistants				
123	e450	Individual attitudes of health professionals				
124	e460	Societal attitudes	X	X	X	X
125	e465	Social norms, practices and ideologies				
	e5	<i>Services, systems and policies</i>				
126	e525	Housing services, systems and policies				
127	e540	Transportation services, systems and policies				X
128	e550	Legal services, systems and policies				
129	e555	Associations and organizational services, systems and policies				
130	e560	Media services, systems and policies				
131	e570	Social security services, systems and policies				
132	e575	General social support services, systems and policies				
133	e580	Health services, systems and policies	X	X	X	X
134	e585	Education and training services, systems and policies			X	X
135	e590	Labour and employment services, systems and policies				

X denotes included in the Brief ICF Core Set. Because of the hierarchical order of the classification, including a second level category automatically includes the third and fourth level categories listed underneath the second level category. ICF, International Classification of Functioning, Disability and Health paediatric version.

Overall, the experts advocated strongly for the inclusion of categories that were meaningful, practical and relevant for children and youth with CP. Consequently, five ICF Core Sets were created for this population. An important

characteristic of the Core Sets is the consideration of developmental trajectories that children and youth with CP follow while they grow. The Common Brief Core Set allows the continuing description of functioning over time,

as its 25 categories are embedded in each age-specific Brief Core Set. Additionally, the age-specific Brief Core Sets allow the description of areas of functioning unique to each age-group.

While the Comprehensive ICF Core Set includes a good representation of all relevant aspects of functioning in children and youth with CP, some functional areas are not fully represented in the Brief ICF Core Sets. For example, areas of d3–Communication and d1–Learning and applying knowledge are not covered in the Common Brief Core Set and are partially covered in the age-specific Brief Core Sets.

Of note the concept of QOL is not included in the ICF; however ‘functioning’ as described in the ICF Core Sets for children and youth with CP may have an impact on QOL. How a child feels (QOL) regarding his or her abilities should be given special attention when setting goals for therapeutic interventions.

Applications of the ICF Core Sets for children and youth with CP

The ICF Core Sets for children and youth with CP can be applied in clinical practice, research, teaching and administration. To facilitate the application of the Core Sets we provide user instructions that accompanied the Core Sets (Appendix SII, online supporting information). Briefly, the following steps are recommended.

Step I–selection of type of ICF Core Set

Each of the ICF Core Sets can be used independently. Their use will vary depending on the intended purpose and settings. For example, interdisciplinary assessments of functioning (Comprehensive ICF Core Set), brief clinical encounters (Common Brief or Age-Specific Brief ICF Core Sets).

Step II–description of level of functioning

The categories included in each Core Set guide professionals in identifying the areas of functioning that need to be assessed. Information gathered using patient-reported questionnaires, clinical examinations, clinical tools and/or technical investigations can be used to address the content of the ICF categories.^{6,29}

Step III–rating the degree of functioning

The categories included in the Core Sets should be rated in order to provide a meaningfully descriptive functional profile. The ICF qualifiers can be assigned to each one of the ICF categories to denote needs, functional strengths and/or limitations, as well as environmental and personal factors influencing functioning.²⁰ The use of a rating scale then allows an objective means to plan interventions, including goal-setting, based on the functional profile of this population. It is important to note that the assignment of ICF qualifiers is made using clinical judgement and they should only be used as descriptors of the degree of functioning, not as an assessment tool.

Figure 2 illustrates an application of the Common Brief ICF Core Set for children and youth with CP. The check-

list provides a descriptive functional profile including relevant contextual factors. As shown in Figure 2, checklists can be developed based on the categories included in each Core Set. The checklists serve as a guide for clinicians during assessments to avoid overlooking aspects of functioning that are likely to be of interest for a child or adolescent with CP. Examples of applications of ICF Core Sets can be found elsewhere.^{6,30–33}

Limitations

The findings of this study should be interpreted in light of its limitations. First, despite our efforts some professional groups were underrepresented at the consensus meeting (e.g. speech-language therapists, nurses and social workers). Second, although all WHO regions were represented, the vast majority of participants were from the Americas. Having equal representation of regions might have resulted in inclusion of additional categories related to different cultural backgrounds. Third, although the consensus was to limit the number of age-specific sets to three, adding more age groups might have resulted in additional categories related to developmental issues. Finally, some major functional areas are not fully represented in the Brief ICF Core Sets (e.g., d1–Learning and applying knowledge and d3–Communication). We expect that the application of the Core Sets in day-to-day practice will guide future revisions to address this limitation.

Future directions

Although the ICF Core Sets for children and youth with CP highlight ‘what’ to measure in children and youth with CP, they do not address ‘how’ to measure those areas of functioning. Therefore, the next steps are to identify which measures align with the content of the ICF Core Sets. In addition, we believe that research to create an ICF-based, psychometrically sound measure for children and youth with CP is desirable.

In summary, the ICF Core Sets for children and youth developed in this study provide a novel and standardized approach to describing the functional profile of this population. The diversity of the participants provided a unique opportunity to integrate different perspectives from the health and education sectors, producing valuable ICF-based tools. We believe the ICF Core Sets for children and youth with CP will be a useful contribution to improving the delivery of care, education, assessment and research approaches in the field of CP.

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Body Structures, Body Functions, Activities and Participation		ICF Qualifier ^a								
		challenge								
		0	1	2	3	4				
s110	Structure of brain									
b117	Intellectual functions									
b134	Sleep functions									
b167	Mental functions of language									
b210	Seeing functions									
b280	Sensation of pain									
b710	Mobility of joint functions									
b735	Muscle tone functions									
b760	Control of voluntary movement functions									
d415	Maintaining a body position									
d440	Fine hand use									
d450	Walking									
d460	Moving around in different locations									
d530	Toileting									
d550	Eating									
d710	Basic interpersonal interactions									
d760	Family relationships									
Influence of environmental factors on functioning		facilitator				barrier				
		+4	+3	+2	+1	0	1	2	3	4
e115	Products and technology for personal use in daily living									
e120	Products/technology for personal indoor/outdoor mobility									
e125	Products and technology for communication									
e150	Design, construction and building products for public use									
e310	Immediate family									
e320	Friends									
e460	Societal attitudes									
e580	Health services, systems and policies									
Influence of personal factors on functioning ^b		positive			neutral			negative		
		+			0			-		
pf	Enjoyment of participation									
pf	Coping strategies in relation to pain									

Figure 2: Checklist summarizing the functional profile of a child or adolescent using the Common Brief ICF Core Set for Children and Youth with Cerebral Palsy. ^aHaving a functional challenge may mean an impairment, limitation, restriction or barrier, depending on the construct, e.g., body functions and structures (classified as impairments), activities and participation (classified as limitations or restrictions) or environmental factors (classified as barriers or facilitators).²⁰ ICF Qualifiers in body functions, body structures and activities and participation: 0=no problem; 1=mild problem; 2=moderate problem; 3=severe problem; and 4=complete problem.²⁰ ICF Qualifiers in environmental factors: 0=no barrier/facilitator; +1=mild facilitator; +2=moderate facilitator; +3=substantial facilitator; +4=complete facilitator; 1=mild barrier; 2=moderate barrier; 3=substantial barrier; 4=complete barrier.²⁰ ^bThe component personal factors (pf) does not have ICF categories assigned, therefore some examples of themes representing personal factors are provided.

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SUPPORTING INFORMATION

The following additional material may be found online:

Figure S1: Alphanumeric codes of ICF categories.

Figure S2: ICF Core Sets development methodology, adapted for children and youth with cerebral palsy.⁶

Figure S3: Iterative decision-making process followed at the consensus conference for developing the ICF Core Sets for children and youth with CP.

Table SI: Distribution of working groups.

Table SII: Representation of ICF chapters in the ICF Core Sets for children and youth and CP.

Appendix SI: Participants' characteristics.

Appendix SII: ICF Core Sets for children and youth with cerebral palsy – User Instructions.

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