

NEW ICF CORE SETS FOR ADULTS WITH CEREBRAL PALSY

Opportunities to standardize assessments worldwide

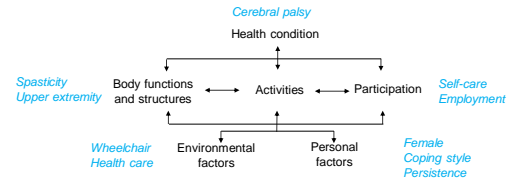
Suzie Noten, Melissa Selb, Elisabet Rodby Bousquet,
Deborah Thorpe, Lorenzo Troenosemito,
Wilma van der Slot, Marij Roebroeck

RUNDAM

ICF Research Branch

Erasmus MC
safing

ICF framework

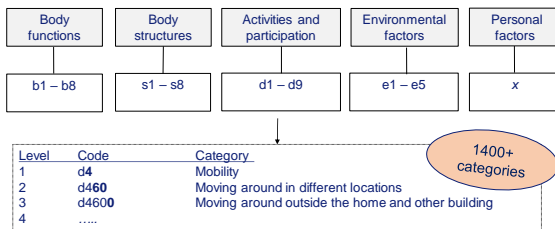


RUNDAM

ICF Research Branch

Erasmus MC
safing

ICF coding



RUNDAM

ICF Research Branch

Erasmus MC
safing

ICF Core Sets for specific health conditions

Aim of ICF Core Sets:

- Applicability of the ICF in clinical practice and research
- An international standard for assessing and reporting on functioning

Available:

- ICF Core Sets for children and youth with CP
- Methodology of WHO and ICF Research Branch



Methodology development of ICF Core Sets

Preparatory Phase	Consensus	Future
Systematic literature review <i>Researchers' perspective</i>	International ICF Consensus Process 1st version of the ICF Core Sets for adults with CP	Testing and validation of the 1st version of ICF Core Sets for adults with CP
Qualitative study <i>Perspective of adults with CP</i>		
Expert survey <i>Professionals' perspective</i>		
Empirical study <i>Clinical perspective</i>		

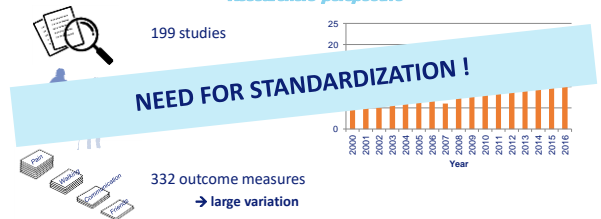
RUNDAM

ICF Research Branch

Erasmus MC
safing

1. Systematic literature review

Researchers' perspective



Benner JL*, Noten S* et al (2019) Outcomes in adults with cerebral palsy: systematic review using the International Classification of Functioning, Disability and Health. DMCN

2. Qualitative study *perspective of adults with CP*



6 focus groups
31 adults with CP without intellectual disability

'The fact that I realize that I am different also gives room for other people to be different.' (44-year-old male, GMFCS level IV)



7 interviews
7 adults with CP with intellectual disability
+ caregiver

Noten S et al (2021) Development of an ICF Core Set for adults with cerebral palsy: capturing their perspective on functioning. DMCN

2. Qualitative study *perspective of adults with CP*

- Q1. Body functions (b): If you think about your body and mind, what does not work the way it is supposed to?
- Q2. Body structures (s): If you think about your body, in which parts are the problems?
- Q3. Activities and participation (d): If you think about your daily life, what are your problems?
- Q4. Environmental factors (e): If you think about your environment and your living conditions, what do you find helpful or supportive?
- Q5. Environmental factors (e): If you think about your environment and your living conditions, what barriers do you experience?
- Q6. Personal factors (pf): If you think about yourself, what is important about you and the way you handle your condition/situation?

Noten S et al (2021) Development of an ICF Core Set for adults with cerebral palsy: capturing their perspective on functioning. DMCN

7

8

3. Expert survey *Professionals' perspective*



32 Countries



126 Health care professionals and researchers



6 Questions

Limaekul C and Noten S et al (2020) Developing an ICF Core Set for adults with cerebral palsy: A Global expert survey of relevant functions and contextual factors. J Rehabil Med

9

4. Clinical study *Clinical perspective*



The Netherlands, Sweden, Thailand and America

101 adults with CP
69 without intellectual disability
32 with intellectual disability

b2. SENSORY FUNCTIONS AND PAIN	
b210 Seeing	
b230 Hearing	
b235 Vestibular (incl. Balance functions)	
b280 Pain	

Noten S et al (2022) An international clinical perspective on functioning and disability in adults with cerebral palsy. Disability and Health

10

ICF categories identified in four preparatory studies

	Body Functions	Body Structures	Activities and participation	Environmental factors	Total
Literature	20	4	43	5	72
Adults with CP	47	7	43	35	132
Experts	20	8	14	21	63
Clinical setting	27	4	53	20	104
Candidate list	48	9	56	41	154

- A broad range and diversity of problems and difficulties
- Environmental factors - facilitators and barriers - are important for everyday functioning

RUNDAM ICF Research Branch Erasmus MC

11

Consensus



25 experts from 15 countries



Wide range of professional backgrounds
e.g., physical medicine and rehabilitation, neurology, orthopaedics, physical therapy, occupational therapy, speech and language therapy, nursing, psychology



Adults with CP and parents

Noten et al (2022) ICF Core Sets for the assessment of functioning of adults with cerebral palsy. DMCN

12

Consensus process

Input: 154 ICF categories

Comprehensive and Brief ICF Core Sets

Online version of the original face-to-face consensus conference

ICF Core Sets

Comprehensive ICF Core Set

- Comprehensively describe the functioning profile
- Multi-disciplinary team

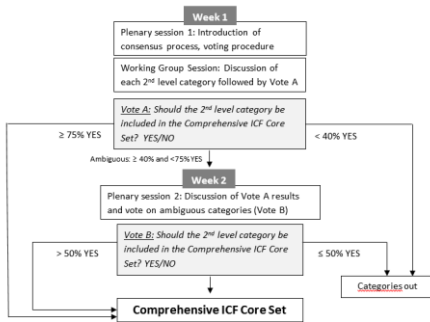
Brief ICF Core Set

- Most essential categories
- To serve as a minimum international standard for assessing and reporting the functioning of adults with CP

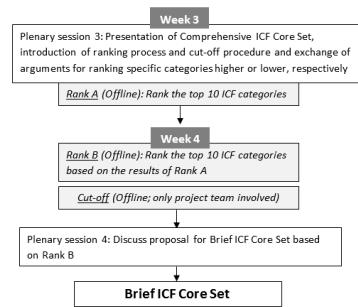
Noten et al (2022) ICF Core Sets for the assessment of functioning of adults with cerebral palsy. DMCN

13

14



15



16

Cultural differences, e.g. religion or family

Feedback on Vote B

b126 Temperament and personality functions

Description

General mental functions of constitutional disposition of the individual to react in a particular way to situations, including the set of mental characteristics that makes the individual distinct from others.

Working Group 1	Yes	No	44 %
4	5		

Working Group 2	Yes	No	75 %
6	2		

Working Group 3	Yes	No	12 %
1	7		

Notes

difficult to express yourself, depending on cognitive ability, difficult to assess

PAGE 2 OF 24

17

ICF

- b BODY FUNCTIONS
 - b1 MENTAL FUNCTIONS
 - b110-b130 Global mental functions (b110-b130)
 - b140-b189 Specific mental functions (b140-b189)
 - b140 Attention functions
 - b144 Memory functions
 - b147 Psychomotor functions
 - b152 Emotional functions
 - b156 Perceptual functions
 - b160 Thought functions
 - b164 Higher-level cognitive functions
 - b167 Mental functions of language
 - b1670 Reception of language
 - b1671 Expression of language
 - b1672 Integrative language functions
 - b1678 Mental functions of language, other specified
 - b1679 Mental functions of language, unspecified

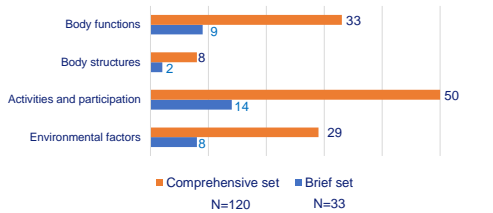
- d ACTIVITIES AND PARTICIPATION
- d1 LEARNING AND APPLYING KNOWLEDGE
- d2 GENERAL TASKS AND DEMANDS
- d3 COMMUNICATION
 - d310-d329 Communicating - receiving (d310-d329)
 - d310 Communicating with - receiving - spoken messages
 - d3100 Communicating with - receiving - simple spoken messages
 - d3101 Communicating with - receiving - complex spoken messages
 - d3108 Communicating with - receiving - spoken messages, other specified
 - d3109 Communicating with - receiving - spoken messages, unspecified

b167 Mental functions of language - Specific mental functions of recognizing and using signs, symbols and other components of a language

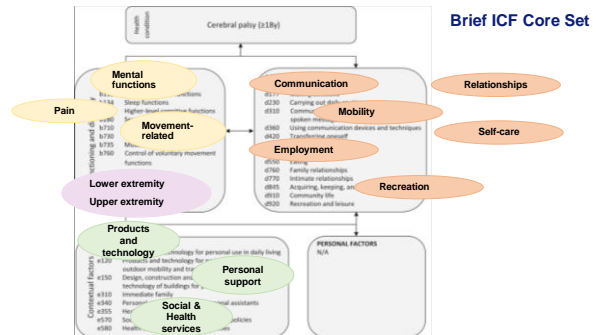
d310 Communicating with - receiving - spoken messages - Comprehending literal and implied meanings of messages in spoken language, such as understanding that a statement asserts a fact or is an idiomatic expression.

18

ICF Core Sets



19



20

ICF Core Sets for adults with CP

- ICF Core Sets provide core areas and assist users by providing a checklist of **what** to measure
- ICF Core Sets support the **standardization** of the assessment and reporting of functioning of adults with CP in clinical practice and research



21

Next steps

- How to measure**
 - Select measurement instruments, such as questionnaires or clinical tests
- Stimulate standardisation of data collection
 - Registers

→ Solid basis for describing the impact of CP at adult age



22

Thank you!

Suzie Noten

The University of North Carolina at Chapel Hill (VS)
 Prince of Songkla University (Thailand)
 Libra Revalidatie en Audiologie
 Uppsala University (Zweden)
 De Hoogstraat Revalidatie
 Rijnland Revalidatie
 Amsterdam UMC
 CP Nederland
 UMCg

RJNDAM

ICF Research Branch

Erasmus MC

23