

NEW ICF CORE SETS FOR ADULTS WITH CEREBRAL PALSY

Opportunities to standardize assessments worldwide

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RJNDAM

ICF Research Branch

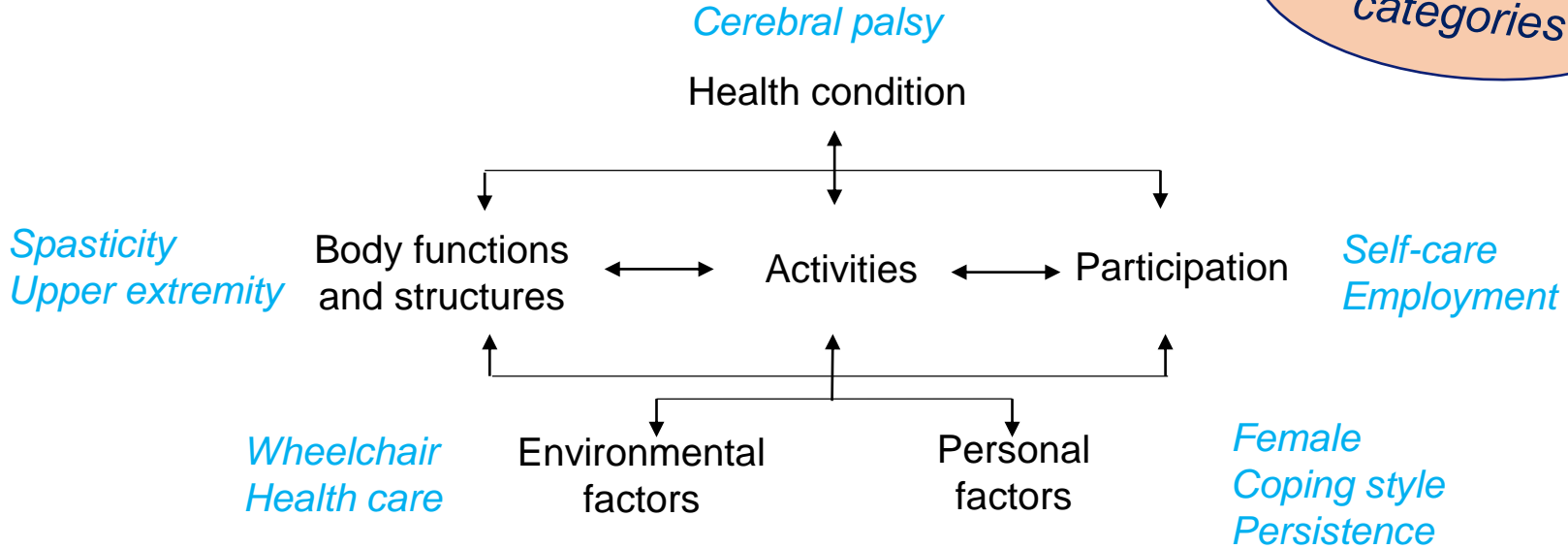
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Universitair Medisch Centrum Rotterdam

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CAPA 2022

ICF framework

1400+ categories



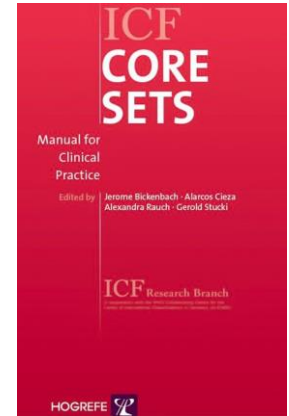
ICF Core Sets for specific health conditions

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 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>		

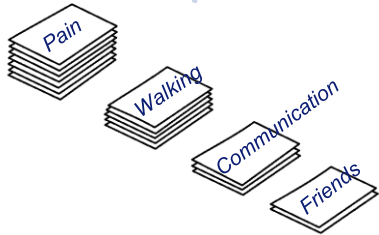
1. Systematic literature review

Researchers' perspective



199 studies

NEED FOR STANDARDIZATION !



332 outcome measures

→ large variation

2. Qualitative study

perspective of adults with CP



6 focus groups

31 adults with CP without intellectual disability

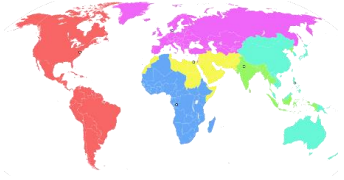


7 interviews

7 adults with CP with intellectual disability
+ *caregiver*

3. Expert survey

Professionals' perspective



32 Countries



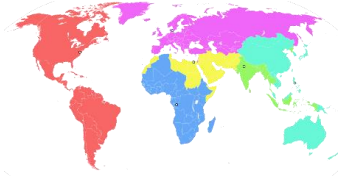
126 Health care professionals and researchers



6 Questions

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 (<i>incl. Balance functions</i>)	
b280 Pain	

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

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



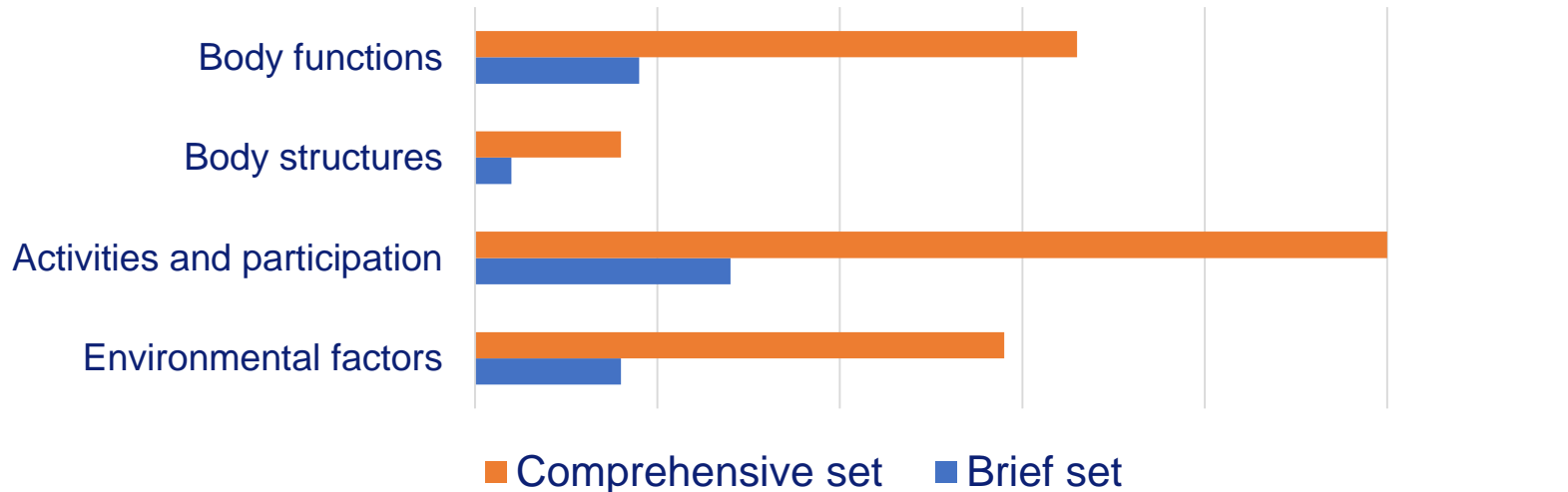
Adults with CP and parents

Comprehensive ICF Core Set (n=120)

- Comprehensively describe the functioning profile
- Multi-disciplinary team

Brief ICF Core Set (n=33)

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



Brief ICF Core Set

Health condition
Cerebral palsy (≥18y)

Mental functions

b134 Sleep functions
Higher-level cognitive functions

Movement-related

b280 Spinal cord functions
b710 Musculoskeletal functions
b730 Mobility functions
b735 Musculoskeletal functions
b760 Control of voluntary movement functions

Lower extremity
Upper extremity

Communication

d177 Making decisions
d230 Carrying out daily activities
d310 Communication functions
spoken messages
Mobility
d360 Using communication devices and techniques
d420 Transferring oneself

Employment

d550 Eating
d760 Family relationships
d770 Intimate relationships
d845 Acquiring, keeping, and using
d910 Community life
d920 Recreation and leisure

Relationships

Self-care

Recreation

Products and technology

e120 Products and technology for personal use in daily living
e150 Products and technology for outdoor mobility and transportation
e150 Design, construction and technology of buildings for personal use

Personal support

e310 Immediate family
e340 Personal and social assistants
e355 Health services
e570 Social policies
e580 Health services

Social & Health services

PERSONAL FACTORS
N/A

Pain

Mental functions

Movement-related

Communication

Mobility

Employment

Lower extremity
Upper extremity

Products and technology

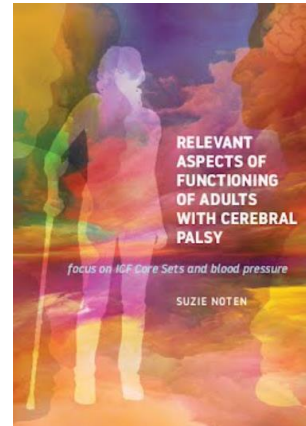
Personal support

Social & Health services

PERSONAL FACTORS
N/A

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



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



Thank you!



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