

Applications of ICF-CY

Development of the ICF-CY core sets for CP

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Outline

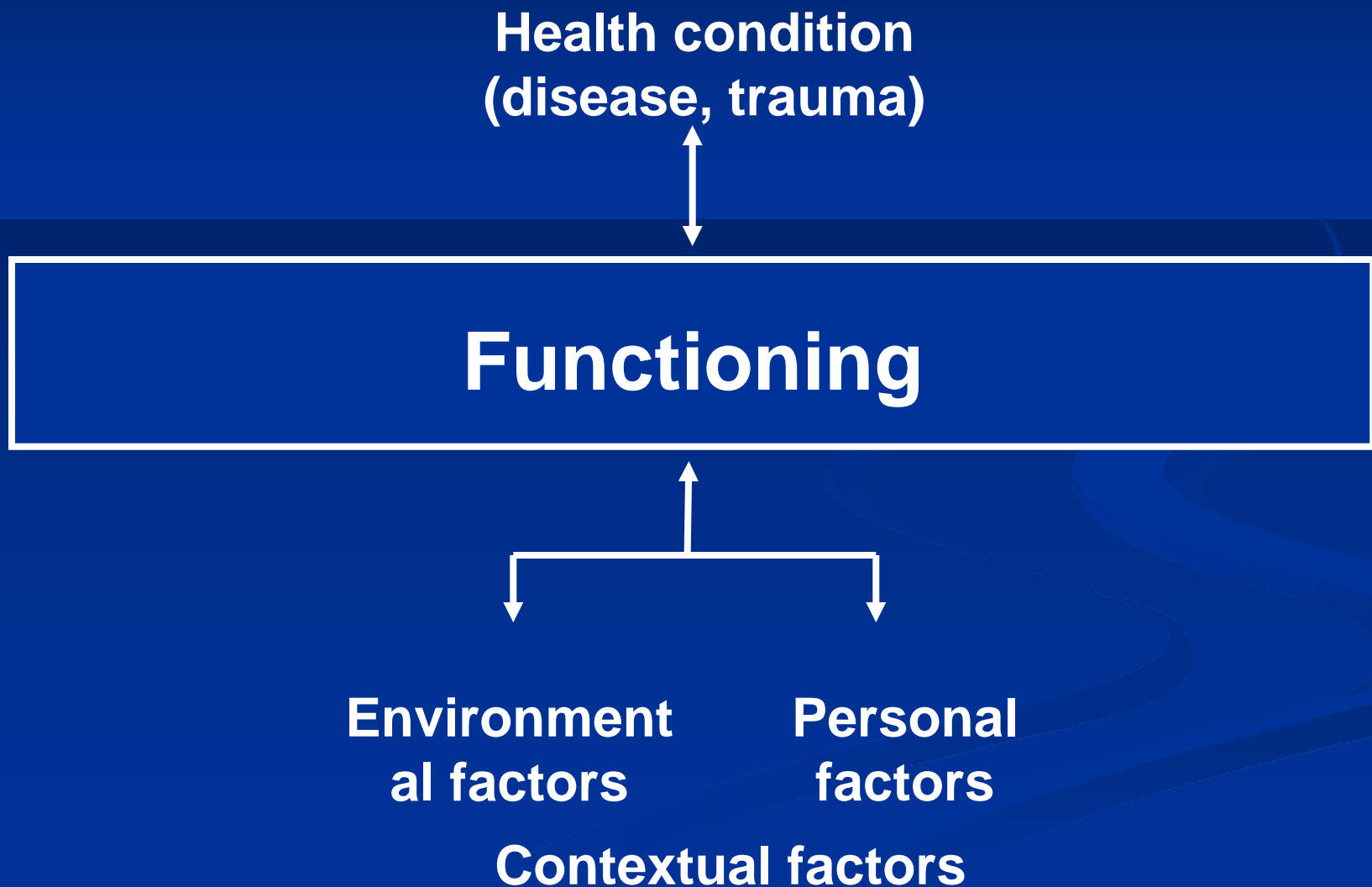
- ICF model
- Development of the ICF-CY core sets for CP
- ICF clinical applications
- ICF-CY clinical applications, ongoing projects

ICF

- In 2001, the International Classification of Functioning, Disability and Health (ICF) was approved by the WHO assembly
- All member states have been asked to implement the ICF in research, social policy, clinical and educational tools and statistical reports
- It is intended to be a **universal classification system**, meaning that it is about all people, not just people with disabilities.
- The ICF enables the users to record useful **profiles of individual's functioning**, disability and health in various domains.

ICF model

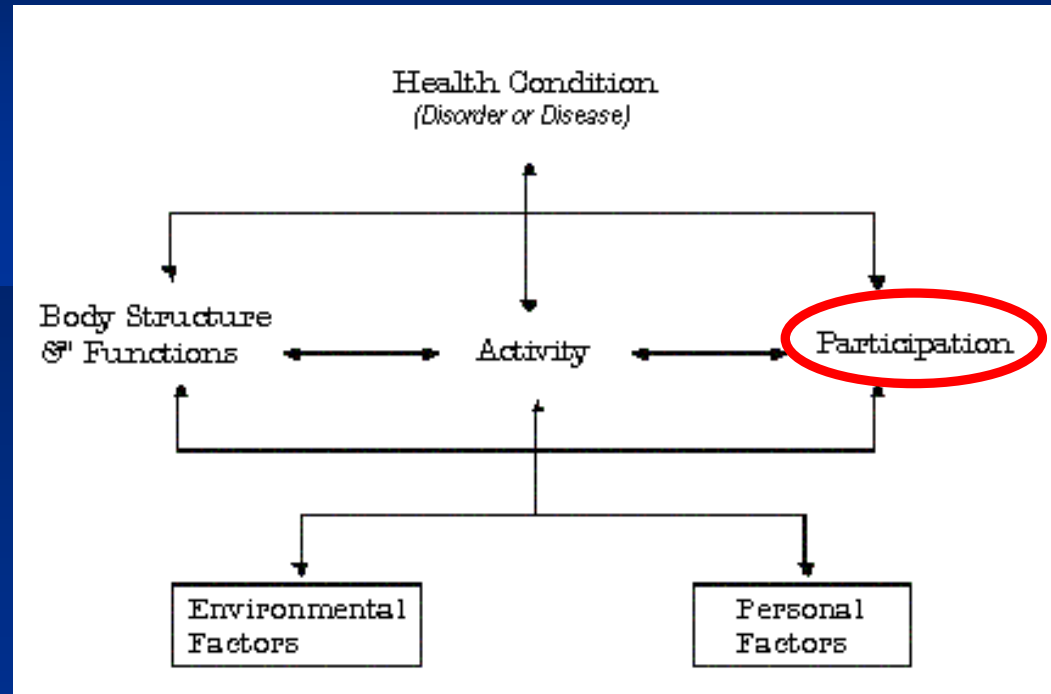
The integrative model of functioning and disability





ICF model: bio-psychosocial model

Part I. Functioning/Disability



Part II. Contextual factors

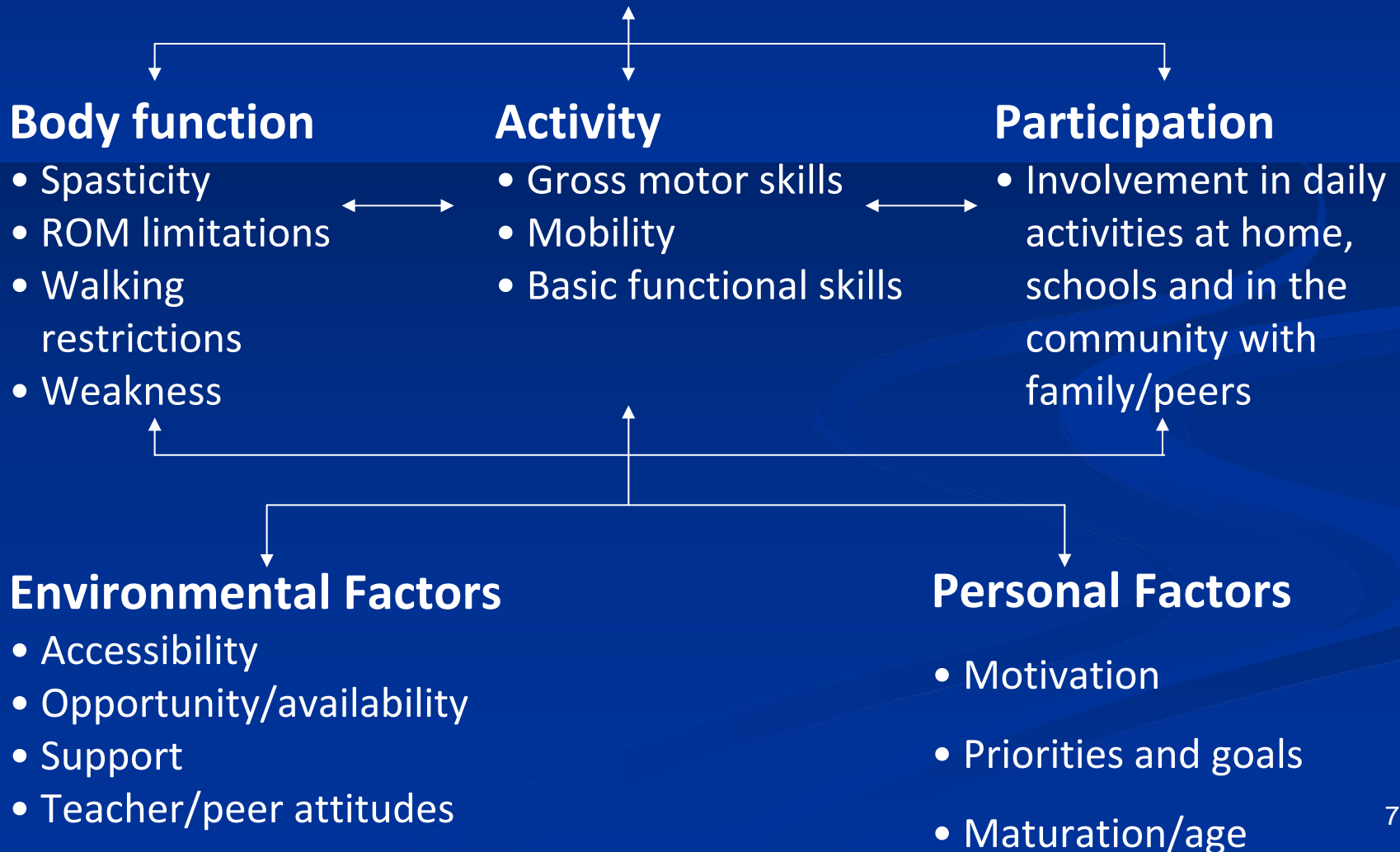
New contributions:

Identification of '**participation**' as an important dimension of health.

All the **components of the model are now linked** to each other (bi-directional arrows), any aspect of function can and probably will affect another, in a non-linear manner.

ICF-CY: example

Cerebral Palsy





ICF model: bio-psychosocial model

- One key change is a **shift in language** from negative terms such as 'impairment', 'disability' and 'handicap' to the **neutral terms** 'body function and structure', 'activity', and 'participation', respectively.
- A second change is that the term 'disability' is now an umbrella term to represent the **dynamic interaction** between person and environment. This change reflects the idea that '**disability**' is a **social construct** involving an interaction of the person and their community or society.

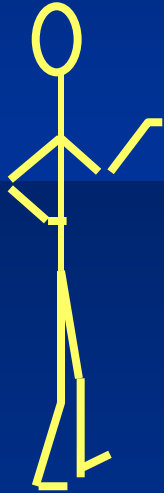
ICF model: bio-psychosocial model

- Contextual factors that may impact a person's health state were added:
 - **'environmental factors'** which can be physical, social, cultural or institutional in nature.
 - **'personal factors'** such as gender, age, education, coping styles, lifestyle, etc.

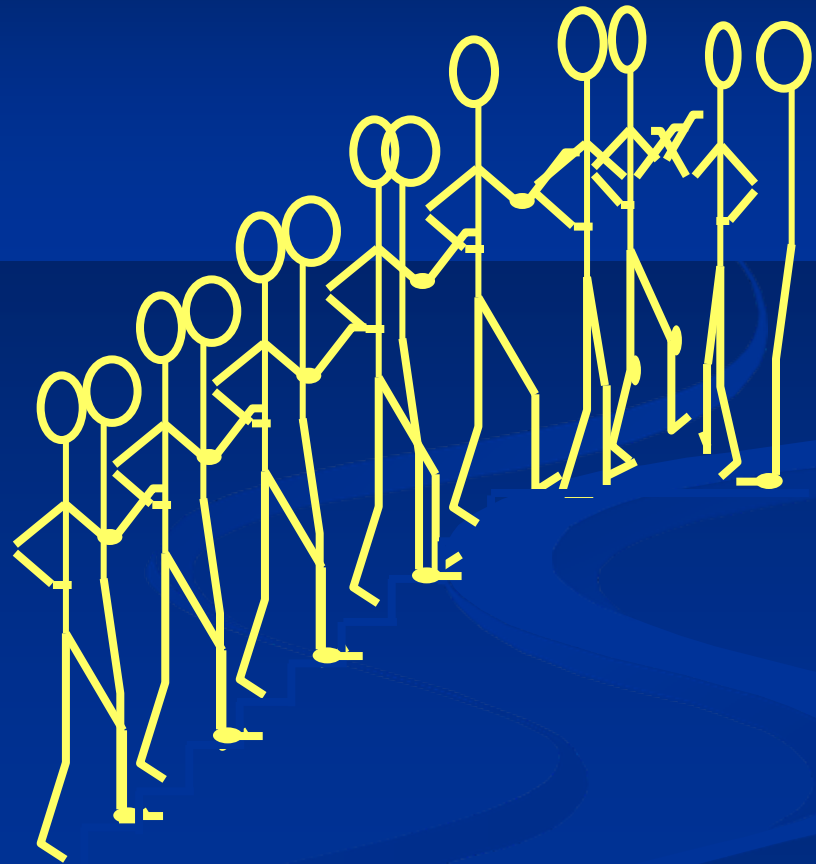
These two contextual factors influence and modify other components of functioning, they **need to be identified**

Functioning is the human experience in relation to

**Body functions
& structures**



Activity & Participation



**in the interaction with health conditions, personal and
environmental factors**

Disability is the human experience of

impaired
body functions
& structures

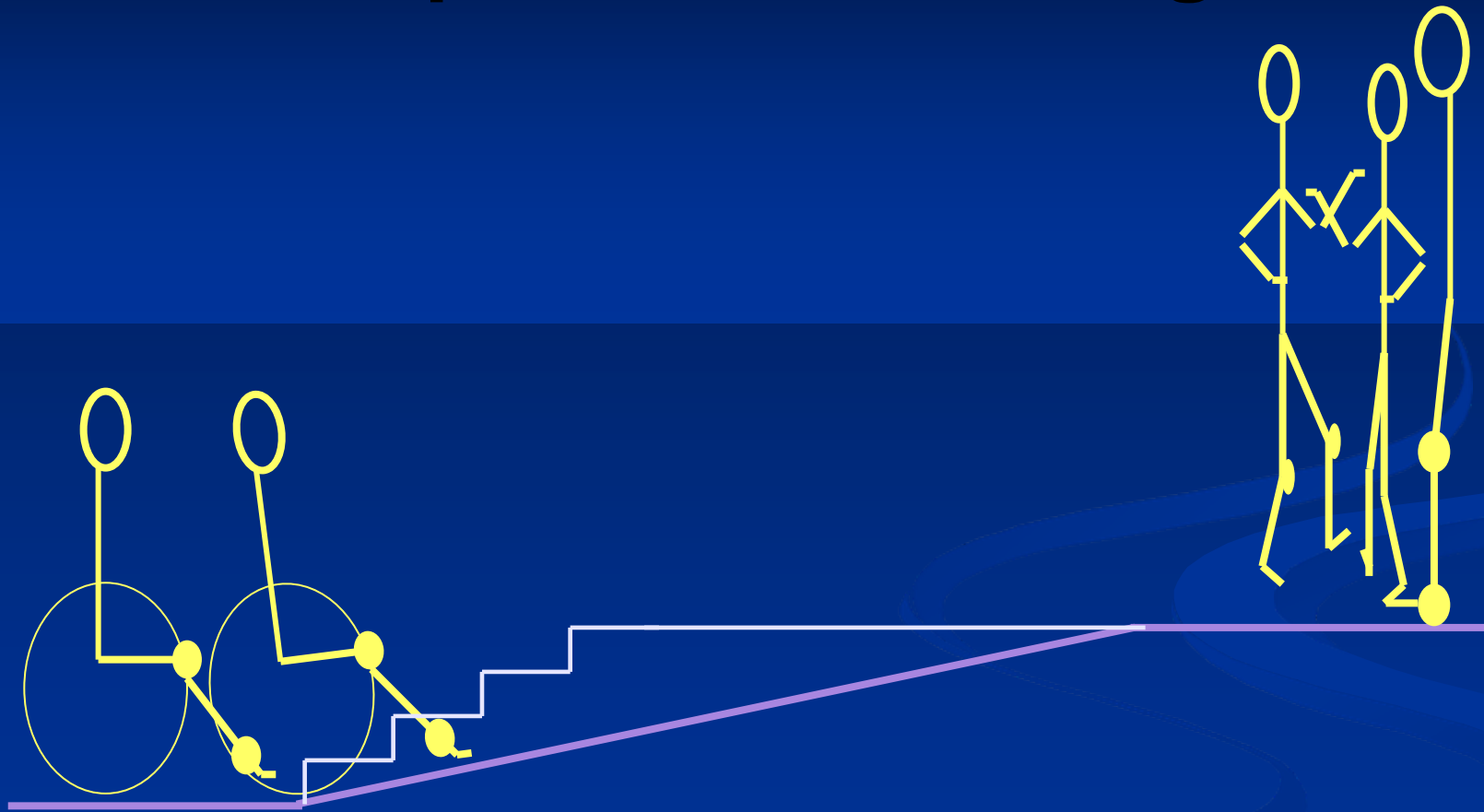


activity limitations
participation restrictions



in the interaction with health conditions, personal and
environmental factors

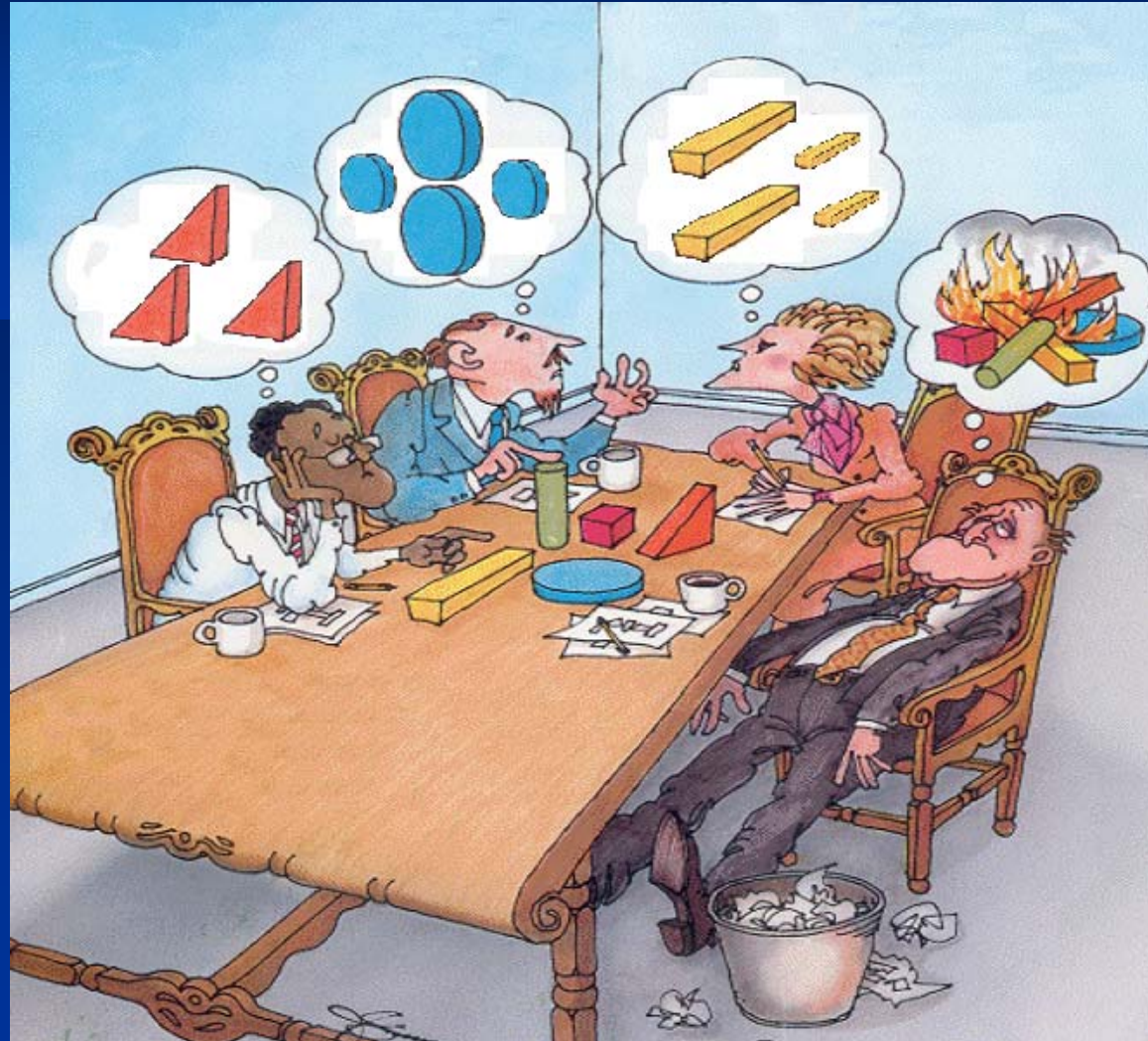
Optimal Functioning



Actual Situation ...

The different health professionals speak their own language in relation to

Functioning



Keep in mind

- ICF Define **"What to measure"**
and not
- **"How to measure"**



ICF-CY

children and youth version



ICF Children and Youth version (ICF-CY)

- Why was a children and youth version developed?
 - ICF was felt to lack constructs that may fully describe functioning in childhood.
 - There was a need for a **common universal language** to describe functional profiles of children and teens.
 - Need for a universal model/framework for describing disability not only medical but social, educational and functional needs of children.

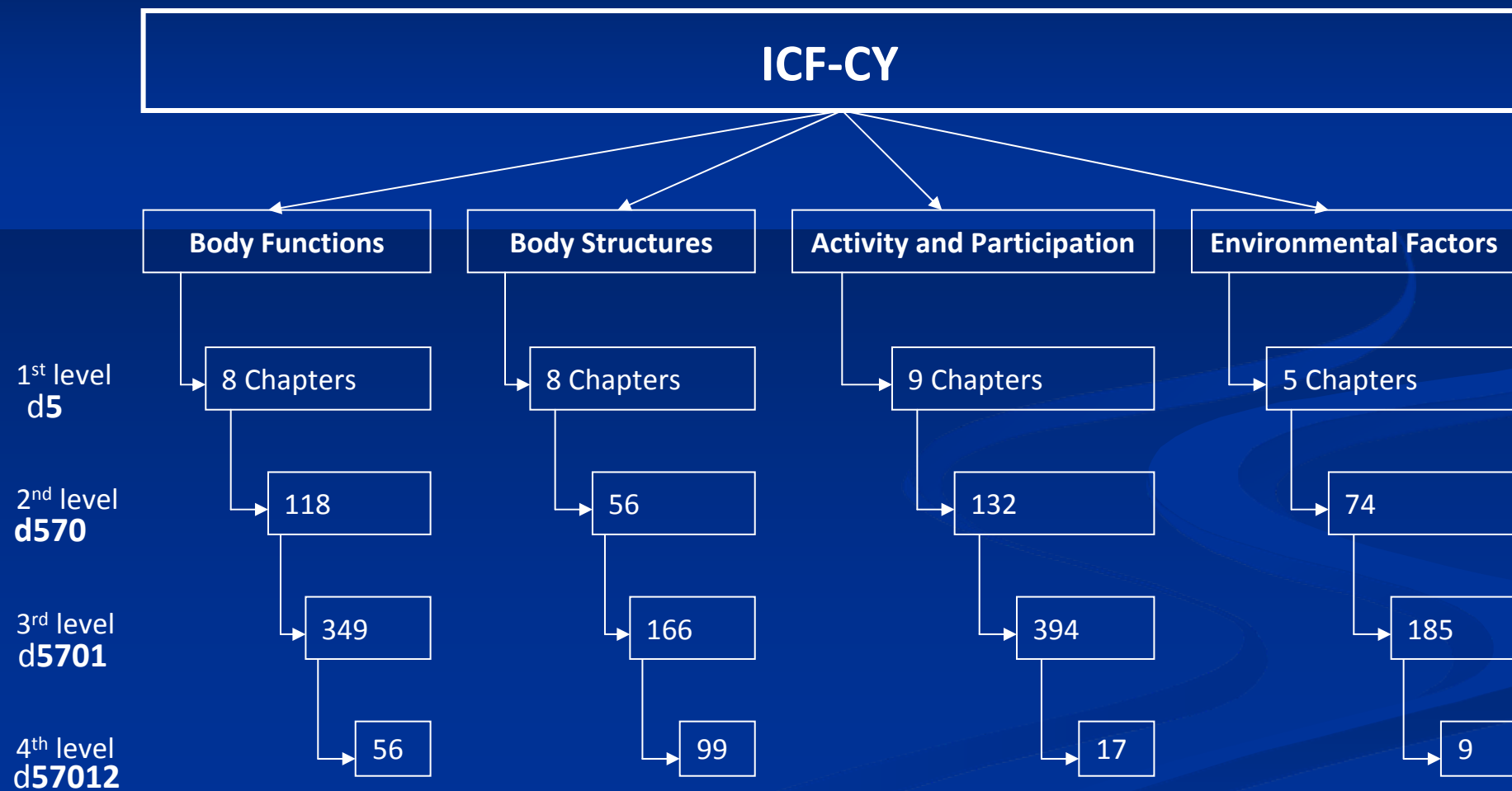
ICF coding

- The units of the ICF classification are called **categories**, denoted by unique **alphanumeric codes**
- Within each component BF (b), BS (s), A&P (d), and environmental factors (e), categories are organized in a hierarchically nested structure as follows:
 - **d5 self-care** (first/chapter level)
 - **d570** Looking after one's health (second level)
 - **d5702** Maintaining one's health (third level)
 - **d57021** Seeking advice or assistance from caregivers (fourth level)

Qualifiers

.0	No problem	0-4%
.1	Mild problem	5-24%
.2	Moderate problem	25-49%
.3	Severe problem	50-95%
.4	Total problem	96-100%
.8	Not specified	
.9	Not applicable	

ICF-CY distribution (1685 categories)



ICF-CY content modification

- modifying or expanding descriptions;
- assigning new content;
- modifying inclusion and exclusion criteria;
- expanding generic qualifiers to include developmental aspects.

Development of ICF-CY: new codes

ICF-CY A&P: New Codes: examples	Category
Learning through actions and play	d131
Acquiring language	d133
Following routines	d2300
Indicating need for urination	d53000
ICF-CY Environmental factors: New Codes: examples	Category
Drink (including breast milk)	e1100
Products and technology for play	e1152
Special education & training services	e5833

- 230 codes were added
- 159 codes (65%) on Activity and Participation

ICF-CY: example of new codes

■ Chapter 8- Major Life Areas

■ Play (d805-d809)

■ **d805 Playing- engaging in spontaneous or organized activities with objects/toys or others**

- d8050 solitary play
- d8051 functional play
- d8052 symbolic/pretend play
- d8053 social play

ICF/ICF-CY based tools

- To use ICF in clinical practice, ICF-based tools must be developed and integrated into assessment, intervention and follow up
- ICF core sets were the first approach to provide ICF-based tools in clinical practice and research
- This approach is an ongoing and worldwide process

Development of the ICF-CY core sets for children and youth with Cerebral Palsy

ICF Core Sets

List of ICF categories that serves as international standard for the reporting of functioning in every study involving patients with a determine condition

Think of table 2 in publications!

ICF

International
Classification of
Functioning,
Disability
and
Health



World Health Organization
Geneva

b1
b130
b134
b152
b180
b1801

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s299
s710
s720
s730
s73001
s73011

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d170
d230
d360
d410
d415
d430

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e110
e115
e120
e125
e135
e150

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•
•

ICF Core Set

ICF core sets

- There are two types:
 - *Brief ICF-CY Core Sets* (consisting on 10 to 20 categories) to be rated in all subjects included in a clinical/research study with a specific health condition
 - *Comprehensive ICF-CY Core Sets* (consisting of 70-150 categories) to guide multidisciplinary assessments in subjects with that condition.
- The purposes of the ICF-CY core sets are:
 - to guide clinical research
 - needs assessment
 - interventions and treatments

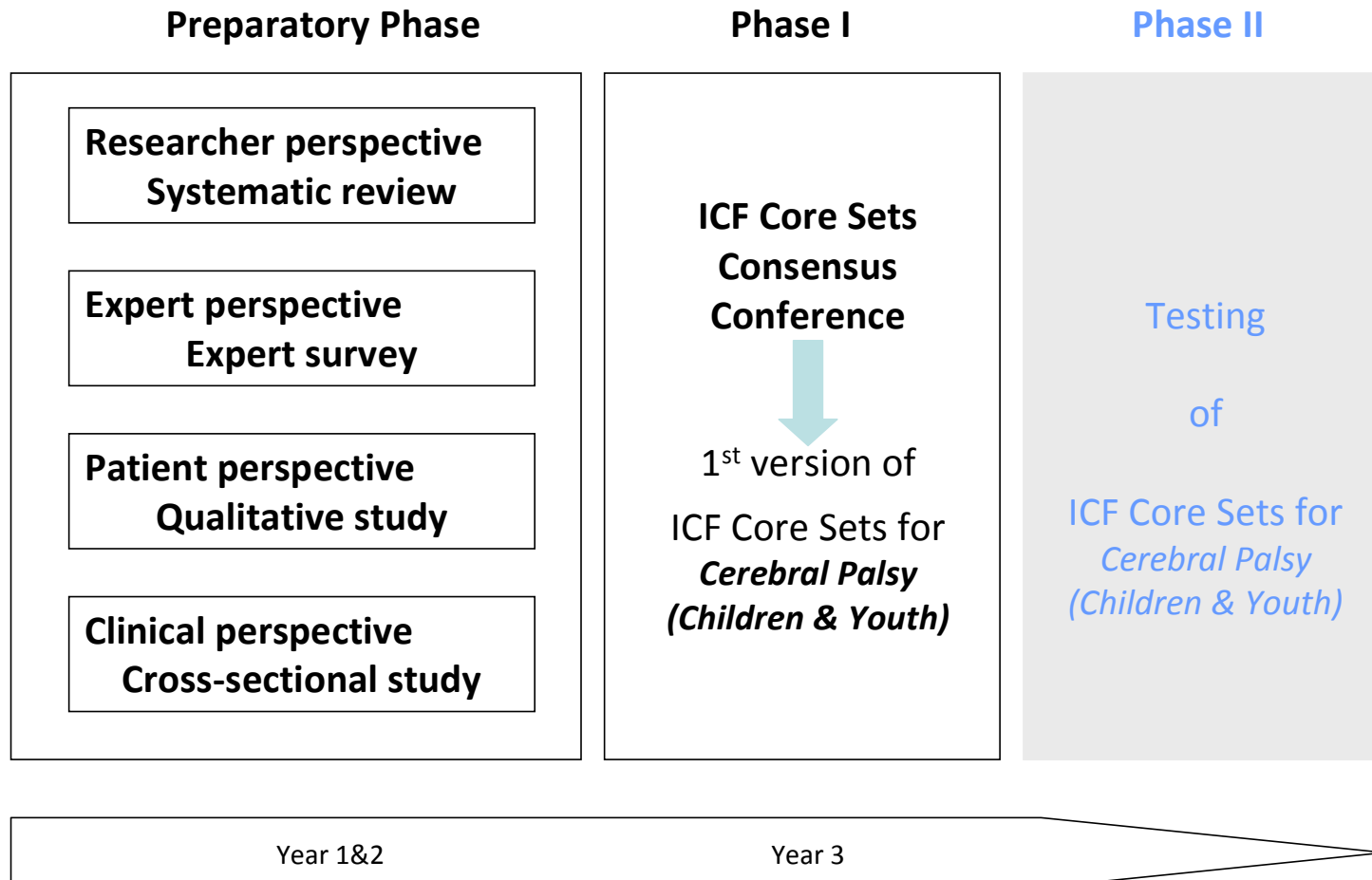
ICF-CY core sets for CP

Objective

- To identify which ICF-CY categories best represent the functional profile of children and youth with CP.

METHODS:

ICF core sets development: WHO guidelines



Systematic Review: Research question

What are the areas of functioning, disability and health reported in published studies on children and youth with CP?



Systematic Review – ICF Core Sets

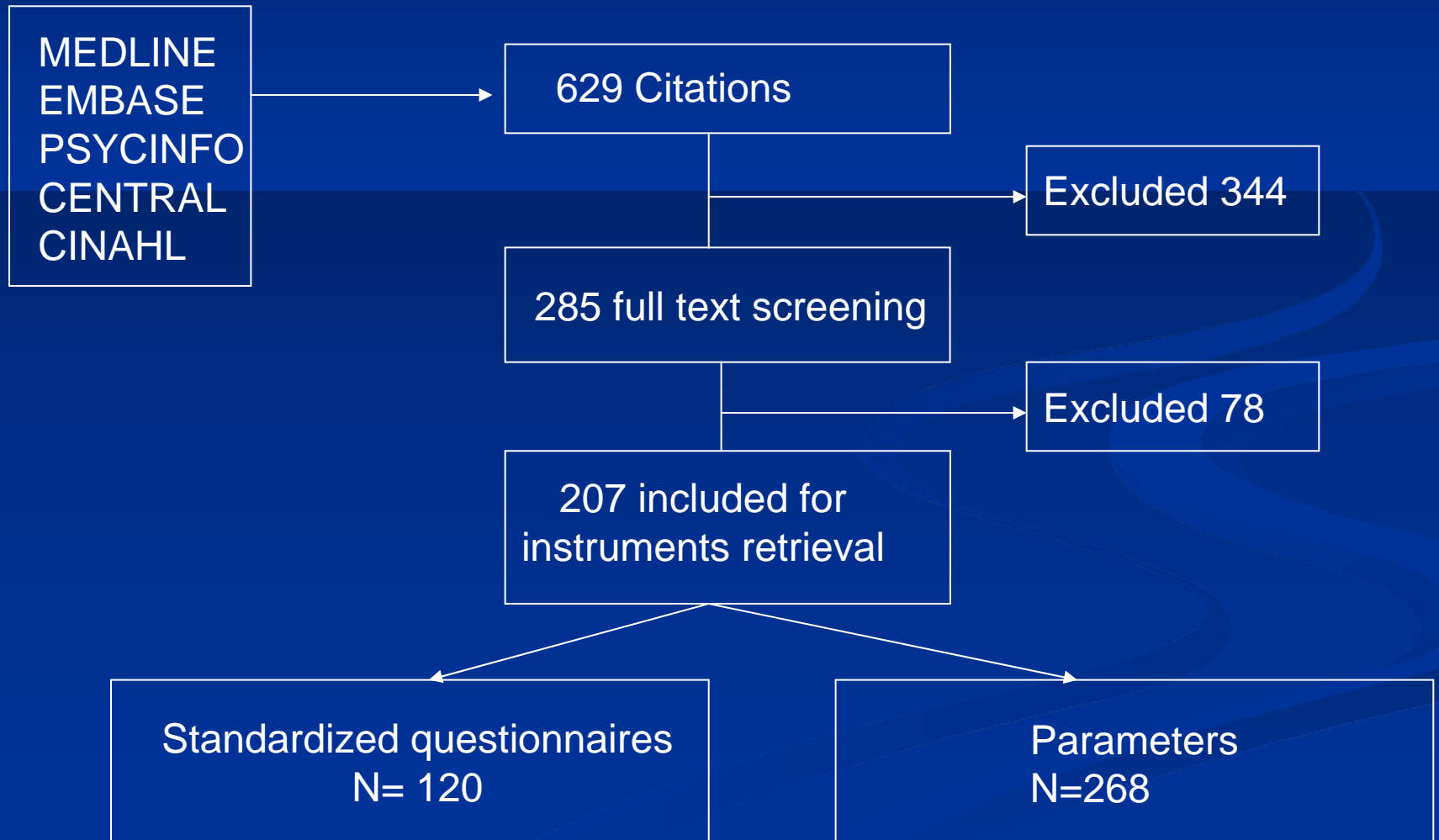
Purpose: To summarize and quantify information on parameters and measurement methods, using the ICF as a reference.



What are the areas of functioning, disability and health that should be considered from the research perspective as candidate categories for the development of ICF-CY Core Sets for children and youth with CP?



CP Systematic review: Methods/results in progress



Meaningful concepts are identified and link to the ICF-CY

original text	<u>meaningful concepts</u>
<ul style="list-style-type: none">- <i>I have no problems with self-care</i>- <i>I have some problems washing or dressing myself</i>	<ul style="list-style-type: none">-self-care- dressing myself- washing myself

Data analysis

Identification
of meaningful
concepts



Linking of
meaningful
concepts to
the ICF-CY

Linking



Frequency
Analysis of
ICF
categories

Global expert survey: Research question

What are the relevant areas of functioning, disability and health for children and youth with a CP from the perspective of health professionals



Expert Survey – ICF Core Sets

Purpose:

To summarize the statements of health professionals using the ICF as a reference:

- the frequency
- the distribution according to the WHO regions
- the distribution according to the professional background

➔ What are the areas of functioning, disability and health that should be considered from the health professional perspective as candidate categories for the development of ICF-CY Core Sets for children and youth with CP?



Global Expert survey: Methods Expert pool

WHO regions	Participants
African	27
Eastern Mediterranean	23
European	96
Americas	182
South-East Asian	25
Western Pacific	84
Total	427

Professional background	
Therapists	217
Physicians	154
Others	46
Total	427

Web-Survey questionnaire

Body functions

If you think about the body and mind of children and youth with Cerebral Palsy, what body functions are of greatest interest?

Body structures

If you think about the body of children and youth with Cerebral Palsy, which body structures are of greatest interest?

Activ & particip.

If you think about the daily life of children and youth with Cerebral Palsy, what functional areas are of greatest interest?

Environm. fact. facilitators

If you think about the physical and social environment and the living conditions of children and youth with Cerebral Palsy, what about the environment is supportive or hindering for them?

Environm. fact. barriers

Personal factors

If you think about children and youth with Cerebral Palsy as individuals, what personal characteristics are important about them?

Global expert survey

Results in progress

- Data collection completed April 28th, 2010
- 194 Respondents
- Further analysis pending:
 - Distribution by WHO regions
 - Distribution by profession

Data analysis



Next steps

- Finish studies in preparatory phase
- Consensus meeting, present all results of preliminary phase to experts.

Based on the evidence develop the brief and comprehensive ICF-CY core sets for children and youth with CP

Presentation at the WHO Consensus Conference

			Empir. Study	Expert Survey	Reviews	Qualit. Study
			%	%	%	n
ICF code	ICF code	ICF title	n= 387	n=110	n=281	n=6
2 level	3 level	4 level				
b134		Sleep functions	24	7	5	5
	b1340	Amount of sleep			1	4
	b1341	Onset of sleep		4	1	1
	b1342	Maintenance of sleep		3	2	
	b1343	Quality of sleep			1	

ICF/ICF-CY applications

Other ICF/ICF-CY based tools

- Customized checklists, based on user needs
 - Assessment sheets
 - Categorical profile
 - Evaluation and follow up

ICF-CY and clinical thinking

Family

- The ICF-CY highlights that families play a key role in impacting child's function.
- Efforts to support and **integrate families in decision making** should be considered a priority (i.e. implementing family-centred services)
- Families can participate in setting goals and can help their children achieve greater functional gains.

Child

- The role of “**personal factors**” in term of **personal choices** and interests in “**self-determined goals**”.
- Children and families will work on things that are important to them.
“**Child-focused/Family-focused approach**”



ICF-CY application: need assessment

- Guide multidisciplinary assessment, identify areas of “need” from the child, family and team perspectives.
- Allows comparison from baseline and subsequent follow up visits.
- Examples: Spinal cord injury (Swiss paraplegic centre),

Table 1: Assessment sheet

	Body-Structures / Functions	Activities / Participation
Patient's Perspective	<p>Sometimes I can't sleep because of my snoring neighbor</p> <p>I have pain in my lower belly</p> <p>I have pain in my right upper arm</p> <p>My sensitivity is not like it used to be before the injury</p> <p>Currently I gain bodyweight</p> <p>My body temperature increases due to heat</p> <p>I have muscles that are weak</p> <p>My muscles exhaust faster</p> <p>I have a risk for pressure sores (especially on my back)</p>	<p>I need support in transferring from bed to wheelchair</p> <p>Currently, I can't transfer into the car by myself</p> <p>I hope to improve putting objects down with my hands</p> <p>I can't pick up things</p> <p>At the moment, I can do less with my right arm</p> <p>Driving long distances with the wheelchair is exhausting</p> <p>I need support in dressing</p> <p>I need support in washing myself</p> <p>I can't drive the car by myself</p> <p>No sporting activity</p> <p>I want to spend time with my friends</p> <p>I would like to go home for the weekend</p> <p>Playing computer games</p> <p>I would like to drive a motorbike</p> <p>Maybe I will work in the summer</p> <p>I want more independence</p>
Health Professionals' Perspective	<p>Sleeping is impaired</p> <p>Touch functions impaired related to diagnosis</p> <p>No proprioceptive functions related to diagnosis</p> <p>Fecal continence completely impaired</p> <p>Urinary continence completely impaired</p> <p>Mobility of joints of right upper extremity reduced by surgery</p> <p>Muscle power functions of upper extremity reduced</p> <p>Muscle spasticity existing but without influence on functioning</p> <p>Endurance of muscles of upper extremity</p> <p>Reflex functions impaired regarding to diagnosis</p> <p>Prop-up functions of arms reduced, e.g. not allowed</p> <p>Scars are healed</p> <p>Structure of the skin — at risk</p>	<p>Completely limited in changing body positions</p> <p>Completely limited in transferring from seat to seat</p> <p>Grab functions reduced</p> <p>Use of hand and arm reduced</p> <p>Moving the manual wheelchair not allowed</p> <p>Completely limited in washing body parts</p> <p>Partially limited in caring for body parts</p> <p>Completely limited in toileting</p> <p>Completely limited in dressing</p> <p>Partially limited in eating</p> <p>Partially limited in drinking</p> <p>Carrying out daily routine limited</p>

Environmental Factors	Personal Factors
Assistive devices for daily living	25-year-old male
Manual / electrical wheelchair	Single, living on his own
Adapted car	Plasterer, unemployed
Wheelchair-adapted flat	Poor purposefulness
Disability payment, Social welfare	I have adapted to loss of functions
Ambulant care 2x daily	Being patient is difficult
My family is important to me	Passive lifestyle
My friends are important to me	Poor compliance
My cat is important to me	Poor sense of responsibility
Fellow human beings are mainly friendly	
Care in Rehabilitation is good	



ICF-CY: in intervention

- The ICF provides an opportunity to talk with children and parents about a different set of primary goals - goals that address function (activity) and social engagement (participation).
- Providers need to plan interventions that target all ICF components, and distance themselves from impairment-based intervention that may focus only on Body structure/body function

Table 2: Intervention table

* The values are rated within the ICF qualifier

	Intervention target	Intervention	Phy	Nurse	PT	OT	Psych	First value*	Final value*
Body function / -structure	s810 Structure of the skin	Daily monitoring		x				0	0
	b134 Sleep functions	Daily monitoring		x				2	2
	b28012 Pain in lower belly	Medication	x					2	2
	b28014 Pain in the right upper limb	Medication	x					3	3
	b7101 Mobility of several joints	Active / passive exercises based on treatment scheme				x	x	2	2
		Adapting brace for limiting ROM					x		
	b7300 Power of isolated muscles (M. triceps brachii)	Active / passive exercises based on treatment scheme. Manual and machine muscle power training 6 weeks postsurgery					x	3	3
	b7401 Endurance of muscle groups	Repetitive exercises. Endurance training with arm ergometer 6 weeks post-surgery				x		3	3
	b7603 Supportive functions of the arms	Repetitive prop-up training 6 weeks post-surgery. Muscle power training with machine 6 weeks post-surgery				x		3	3
	b820 Healing of the scars	Daily wound control	x					0	0
	d230 Carrying out daily routine	Behavioral approach					x	3	3
	d410 Changing basic body position	Support, assistance		x	x			4	4
	d4200 Transferring oneself while sitting	Support, assistance		x				4	4
		Functional training, Prop up training 6 weeks post-surgery			x				

ICF-CY applications: outcome assessment

- Health care providers are encouraged to use the ICF model to guide the selection of outcome measures of interest to their interventions.
- Outcomes need to be **multi-dimensional**, in order to encompass functioning at different levels of body function and structure, activity and participation.
- Outcomes should assess the influence of personal and environmental elements on a person's overall health and well-being.

ICF-CY applications: selection of outcome measures

ICF-CY component	Disease specific measure N (%)		Generic measure N (%)	
	CPCHILD	CPQOL	CHQ	HUI-3
Body function	7(11.5)	14 (18.9)	43 (28.1)	54 (54.5)
Activity & Participation	46 (75.4)	27 (36.5)	60 (39.2)	25 (25.3)
Environmental Factors	2 (3.3)	22 (29.7)	10 (6.5)	16 (16.2)
Personal Factors	0 (0)	4 (5.4)	4(2.6)	0 (0)
Others	6 (9.8)	7(9.5)	36 (23.5)	0 (0)
Total no concepts	61	74	153	99

ICF-CY applications: evaluation/ follow up

- ICF-based tools provide a systematic approach to assess response to treatment over time (compare first assessment with follow up evaluations)

		Assessment							Evaluation													
Global Goal: Ambulant care only once daily			<div></div>						2		not evaluated yet					-						
Service-Program Goal: Weekend holiday			<div></div>						2		not evaluated yet					-						
Cycle goal 1: Independent transferring while sitting			<div></div>						1		<div></div>					-						
Cycle goal 2: Hand and arm use: Drinking			<div></div>						1		<div></div>					+						
Cycle goal 3: Carrying out daily routine (Treatments)			<div></div>						1		<div></div>					-						
ICF categories			ICF Qualifier					Goal relation	Goal Value		ICF Qualifier					Goal achievement						
		problem	0	1	2	3	4			problem	0	1	2	3	4							
b134	Sleep functions		<div></div>					SP	1		<div></div>					-						
b28012	Pain in stomach and abdomen		<div></div>					SP	1		<div></div>					+						
b28014	Pain in upper limb		<div></div>					1,2	0		<div></div>					+						
b7101	Mobility of several joints		<div></div>					2	0		<div></div>					+						
b7301	Power of muscles of one lim		<div></div>					2	2		<div></div>					+						
b7401	Endurance of muscle groups		<div></div>					1,2	1		<div></div>					+						
b7603	Supportive functions of the arms		<div></div>					1	2		<div></div>					+						
b820	Repair functions of the skin		<div></div>					SP	0		<div></div>					+						
s810	Structure of areas of the skin		<div></div>					SP	0		<div></div>											
d410	Changing basic body positions		<div></div>					1	1		<div></div>					-						
d4200	Transferring oneself while sitting		<div></div>					1	1		<div></div>					-						
d440	Fine hand use		<div></div>					2	1		<div></div>					+						
d445	Hand and arm use		<div></div>					2	2		<div></div>					+						
d510	Washing oneself		<div></div>					SP	3		<div></div>					+						
d520	Caring for body parts		<div></div>					SP	3		<div></div>					+						
d530	Toileting		<div></div>					SP	3		<div></div>					+						
d540	Dressing		<div></div>					SP	3		<div></div>					-						
d550	Eating		<div></div>					SP	2		<div></div>					+						
d560	Drinking		<div></div>					SP	1		<div></div>					+						
			facilitator		barrier							facilitator		barrier								
			4+	3+	2+	1+	0	1	2	3	4		4+	3+	2+	1+	0	1	2	3	4	
pf	Compliance		<div></div>					3	0		<div></div>					-						
pf	Sense of responsibility		<div></div>					3	0		<div></div>					-						
pf	Purposefulness		<div></div>					3	0		<div></div>					-						

ICF-CY application: research/teaching

- Researchers and educators are also encouraged to apply the ICF model to their practices. (research studies and educational curriculum)
- Studies on childhood disability should include dimensions of **activity and participation, and environmental factors**, to capture the complex, interactional nature of the life experiences of children with disabilities and their families.

ICF-CY: Other applications

- Management:
 - Managers and decision makers can use the ICF model and classification system **to guide the development of policies** and procedures that reflect current views and beliefs about the biopsychosocial nature of health and disability.
- Surveillance: set of categories to be included in surveys to document **prevalence of functional limitation** by conditions (i.e. PALS)
- Administrative: set of categories **to determine eligibility criteria**, service provision, reimbursement and follow-up

ICF-CY clinical applications, ongoing projects in Canada

Manitoba ICF-CY project

- Objective: to create a single outcome measure to describe the functioning of children and youth (0-21 years) receiving PT and/or OT Therapy services
- Methods:
 - Selection of 23 ICF-CY categories, all from A&P
 - re-wrote the definitions for the 0-4 qualifier scale, from the perspective of how much adaptation, supervision or assistance the client requires to complete the task.
 - Calculate a FUNCTIONAL SCORE (severity of needs)
- Pilot study, goal to use an electronic form for the province
- PI: Sandy Loewen, Senior Physiotherapist, Co-Chair, PT OT Pediatric Clinician's Network

ICF-CY categories- Physiotherapy

Changing Basic Body Position –lying (d4100)	Transferring Oneself While Sitting (d4200)
Changing Basic Body Positions –sitting (d4103)	Walking Short Distances (d4500) , Walking Long Distances (d4501)
Maintaining a Sitting position (d4153)	Moving Around Using Equipment (d465)
Maintaining a Standing Position (d1454)	Climbing (d4551) Running (d4552)
Jumping (and/or Hopping) (d4553)	Recreation and Leisure (d920)

ICF-CY categories- Occupational Therapy

Acquiring Skills (d155) Acquiring Skills to use writing implements (d1450)	Drinking (d560)
Caring for Body parts (d520)	Eating (d550)
Complex Interpersonal Interactions (d720)	Fine Motor (d440)
Handling Stress (d240)	Focusing Attention (d160)
Dressing (d540)	Toileting (d530)

Ontario ICF-CY project

- Objective: to create an abbreviated ICF-CY checklist to assess needs
- Checklist could be used as a standardized approach to assess individual clients' functioning, including their participation, and need for environmental support at intake and for aggregating functional data.
- Setting: Peds Rehab centres, Thames Valey Children's Centre, London Ontario
- PI: Jannette McDougall

Conclusion

In summary, the WHO encourages:

- health professionals,
- social scientists and
- educators

to apply the bio-psychosocial model, proposed by ICF, to service delivery that addresses health and disability from biological, individual and societal perspectives.

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Thanks for your attention

