

Everyday life situations of young children

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Habilitation services in Sweden

Habilitation – acquiring skills

Rehabilitation – regaining lost skills



“A process to reach and maintain individual’s optimal levels within various functional areas and to attain independence and self-determination” (WHO, 2010)

Swedish child and youth habilitation services

- < 18 years
- Congenital disabilities or
Disabilities acquired in early childhood
 - General developmental delay
 - Mobility disabilities
 - Mental retardation
 - Autism spectrum conditions
 - Brain damage acquired < 16 years
 - Hearing disability < 8 years

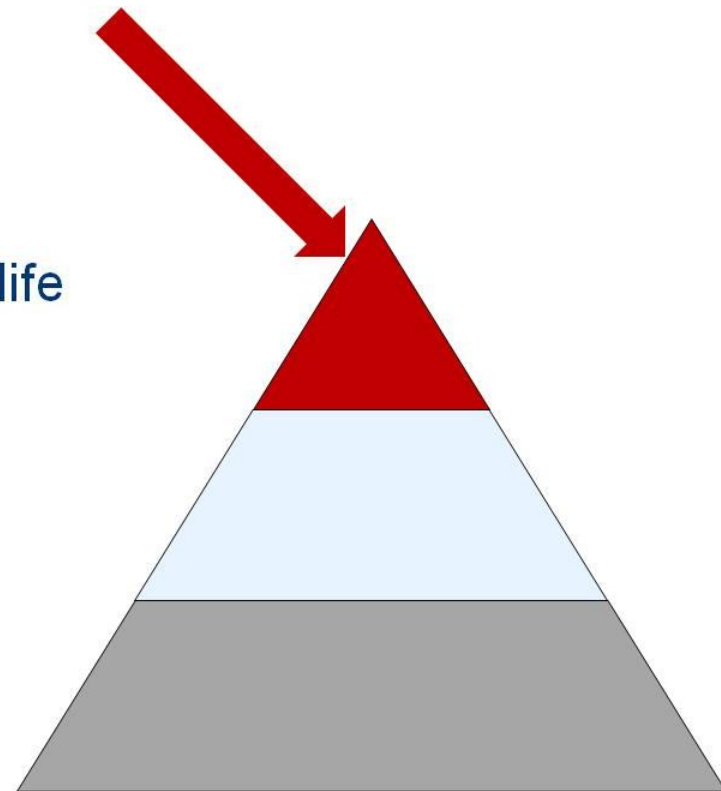


Interdisciplinary habilitation services



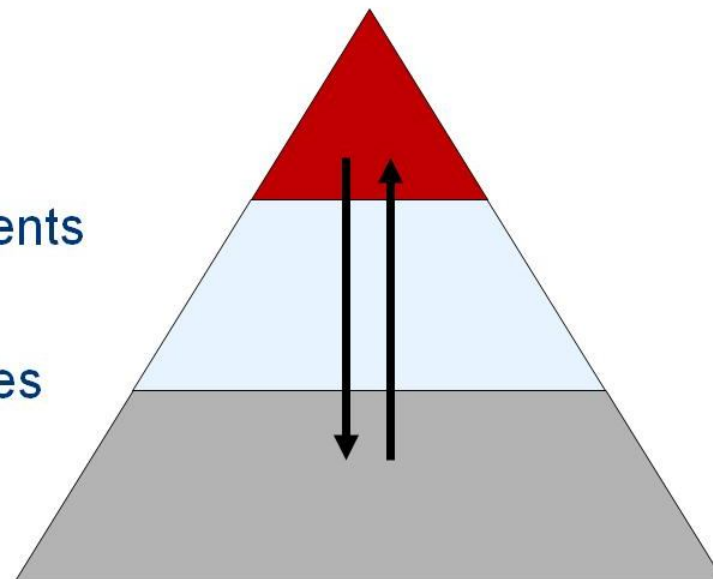
Purpose

- Assessment
- Support child development
- Support families' everyday life
- Provide knowledge
- Help meeting others



Way of working

- Interdisciplinary team
- Individual habilitation plans
- Multidimensional needs
- Polyclinical
- Visits in everyday environments
- Group activities
- Collaboration – other services



Focus on participation in intervention processes

Long-term goal

Opportunities for children with disabilities and their parents to express opinions and take part of professional knowledge during intervention processes

Missing

Structured model to assess child participation in everyday life situations

Interdisciplinary screening tool

Aim of study

Identify ICF-CY categories to be included in **code sets** for three frequent everyday life situations

- ✗ Sleeping
- ✗ Mealtimes
- ✗ Play

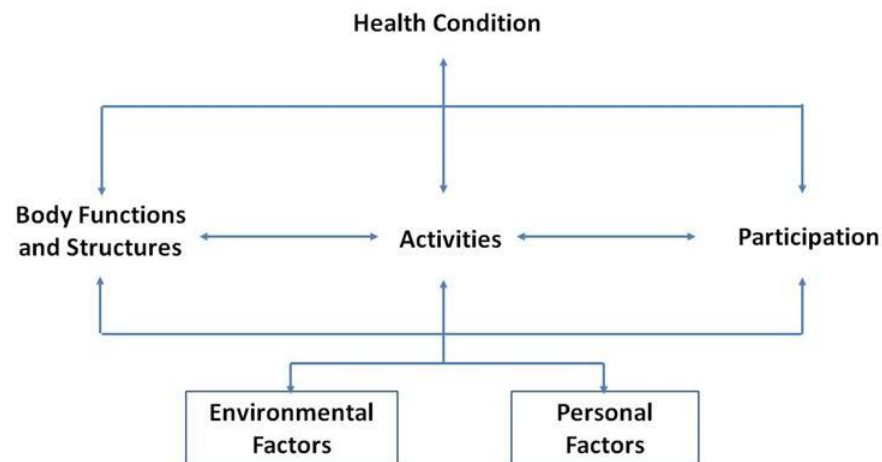
adapted for preschool children aged

0-6 years with or without disabilities

ICF-CY

International **C**lassification of **F**unctioning, disability and health,
version for **C**hildren and **Y**outh

The ICF-CY model



Activities and Participation (d)

- d1 Learning and applying knowledge
- d2 General tasks and demands
- d3 Communication
- d4 Mobility
- d5 Self-care
- d6 Domestic life
- d7 Interpersonal interactions and relationships
- d8 Major life areas
- d9 Community, social and civic life



ICF-CY

The **I**ndividual **C**hild's **F**un
in **C**ertain **Y**ears

!?!?!?

ICF-CY

enhance focus on participation and environment

“The ICF-CY helps us to raise our eyes and see what is most important for each child”



Code sets

A selection of ICF-CY categories that includes the least number of categories possible to be practical, but as many as required to be sufficiently comprehensive



ICF-CY Developmental Code Set for Children

2011. Ellingsen, K.E.& Simeonsson, R.J

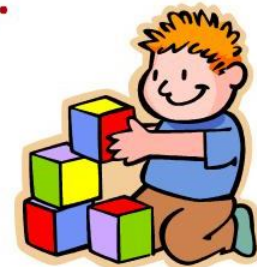
- ▶ Birth to 36 months (0-2)
- ▶ Three through Five Years (3-5)
- ▶ Six through Twelve Years (6-12)
- ▶ Thirteen through Seventeen Years (13-17)



http://www.icf-cydevelopmentalcodesets.com/Home_Page.html

Brief ICF-CY code sets for everyday life situations, e.g.

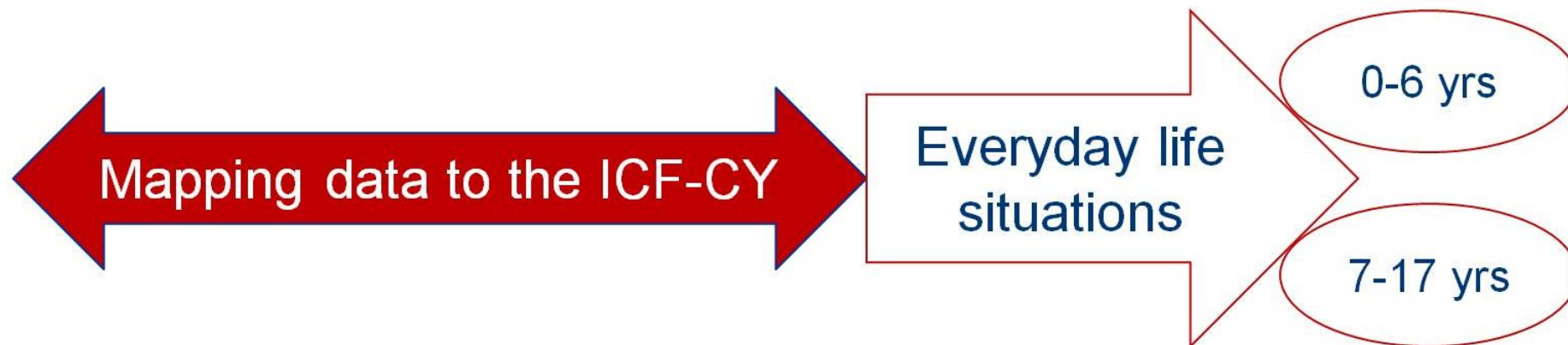
- ▶ Sleeping
- ▶ Mealtimes
- ▶ Play



Systematic literature search

Professional view

Parent's perspectives



Activities
Telling stories
Singing
Having a conversation
Riding a bike
Cutting and pasting
Going to the spaza shop
Visiting shopping malls
Playing arcade games
Mokuku
Eating out
Hair cut/style

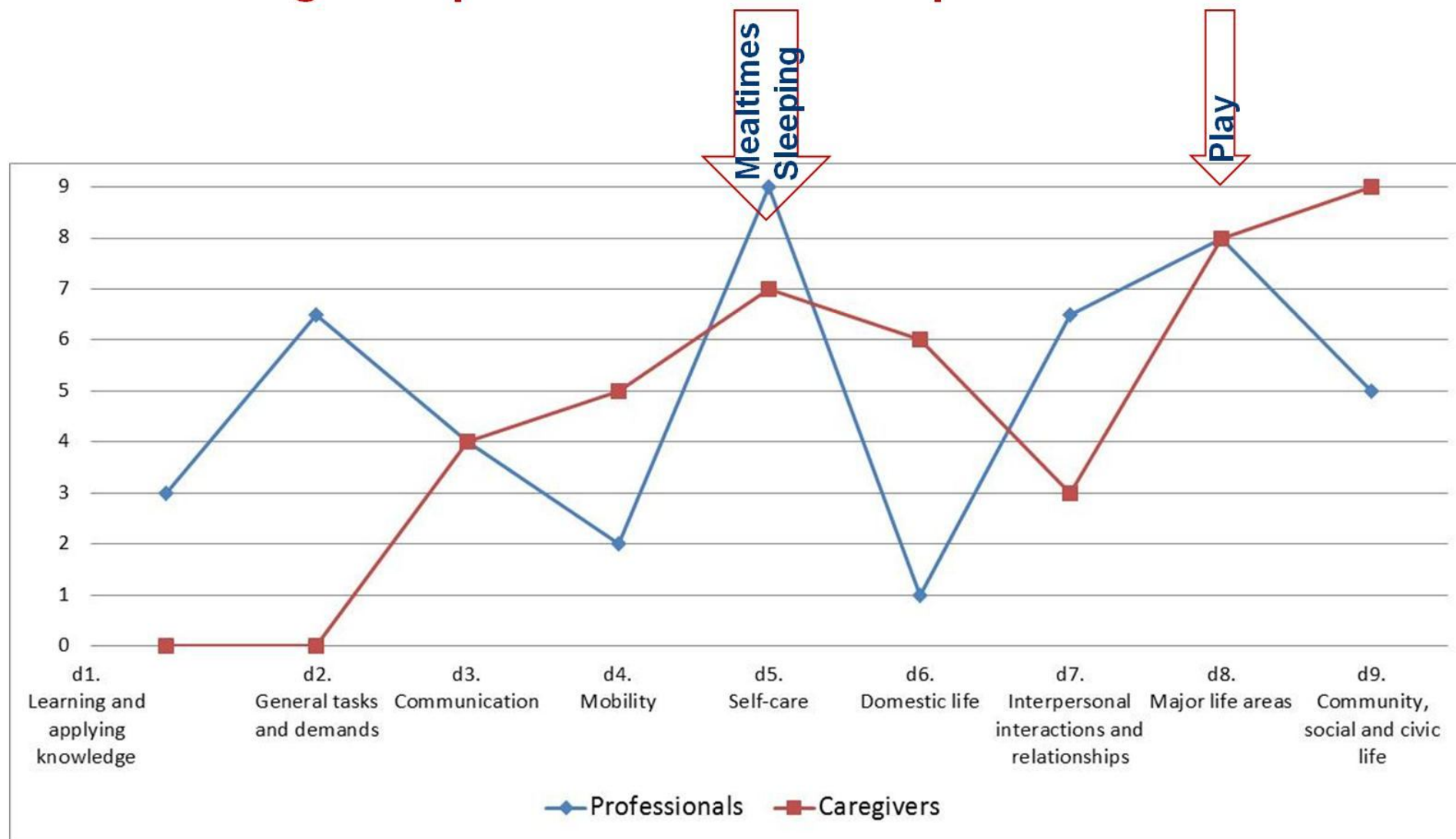
Balton, S. (2009). *Family-based activity settings of typically developing three-to-five-year old children in a low-income African context*. University of Pretoria Pretoria.

Balton, S., Uys K. & Alant, E. Activity settings of typically developing 3-to-5-year old children in a poor urban context.

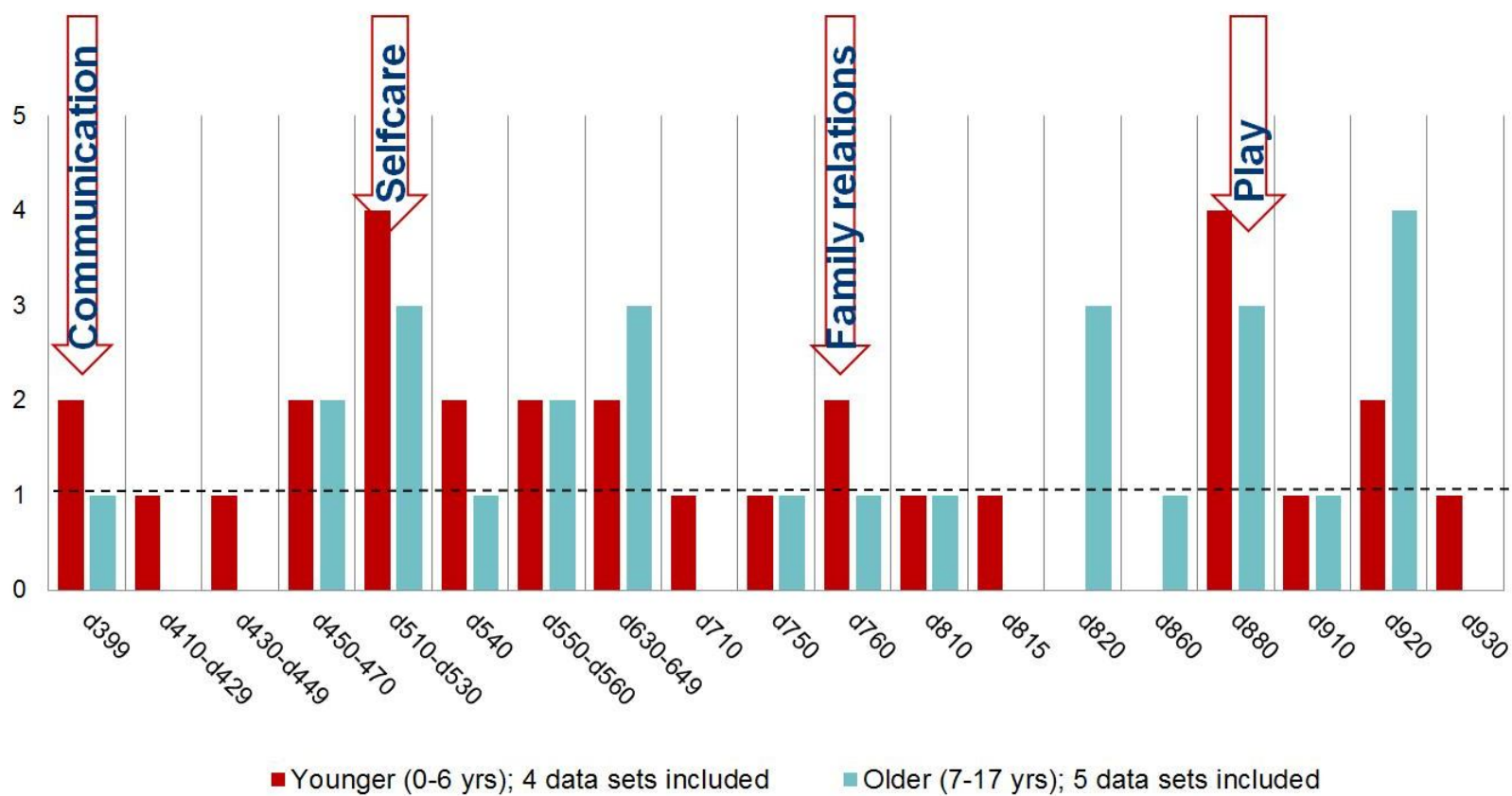
Cieza et al. (2005). ICF linking rules: an update based on lessons learned. *J Rehab Med*, 37(4), 212-218

Activities	ICF code	Category
Telling stories	d330	Speaking
Singing	d332	Singing
Having a conversation	d350	Conversation
Riding a bike	d4750	Driving human-powered transportation
Cutting and pasting	d4402	Manipulating
	d810	Informal education
Going to the spaza shop	d6200	Shopping
	d860	Basic economic transactions
Visiting shopping malls	d9103	Informal community life
Playing arcade games	d9200	Play / games
Mokuku	d445	Hand and arm use
	d9200	Play / games
Eating out	d5501	Carrying out eating appropriately
	d9205	Socializing
Hair cut/style	d5202	Caring for hair

Caregivers-professionals descriptions



Everyday life situations (ages)



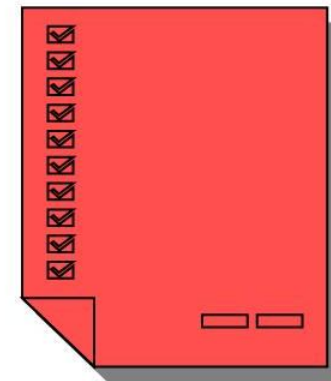
Method

The Delphi Technique

Linstone & Turoff (2002); Weigl et al. (2004); Hasson et al. (2000)

- Consensus-building
- E-mail surveys
- Several rounds
- Expert input
- Assessment of the group view
- Iteration with controlled feedback
- Opportunity to revise view
- Anonymity for individual response

Everyone can make its voice heard



Participants

5 professional experts

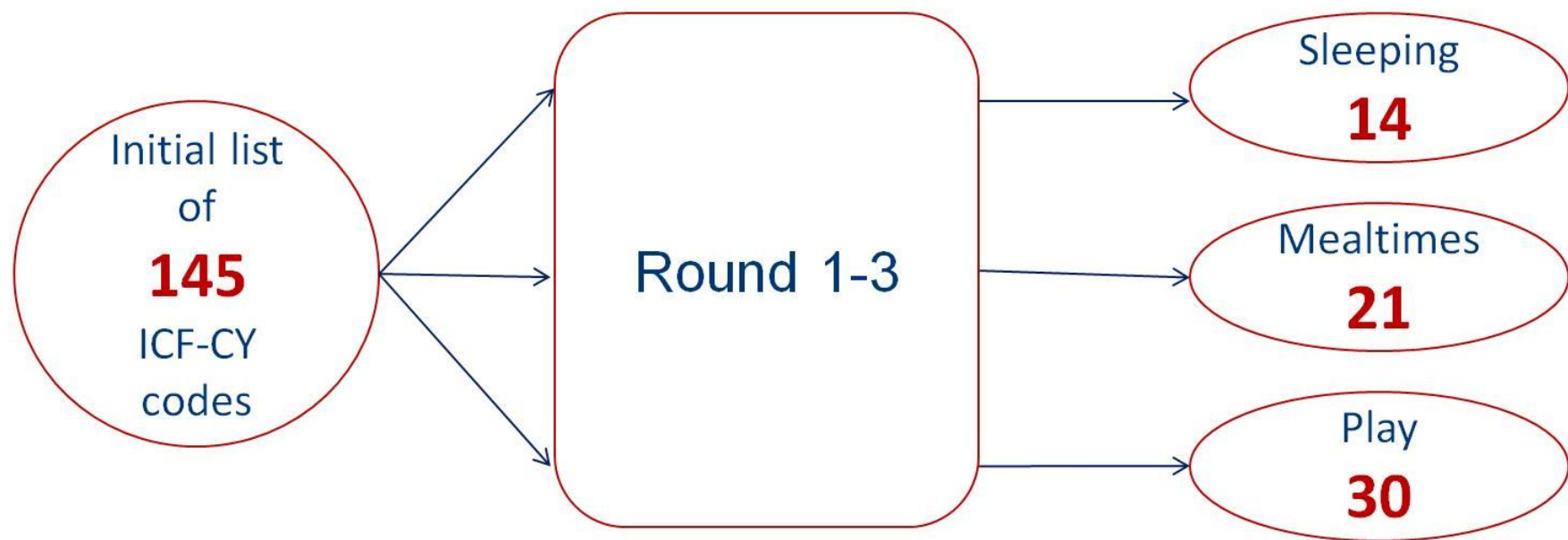
5 interdisciplinary habilitation teams
35 team members
medical, psychological, social, and pedagogical competences

6 parental experts

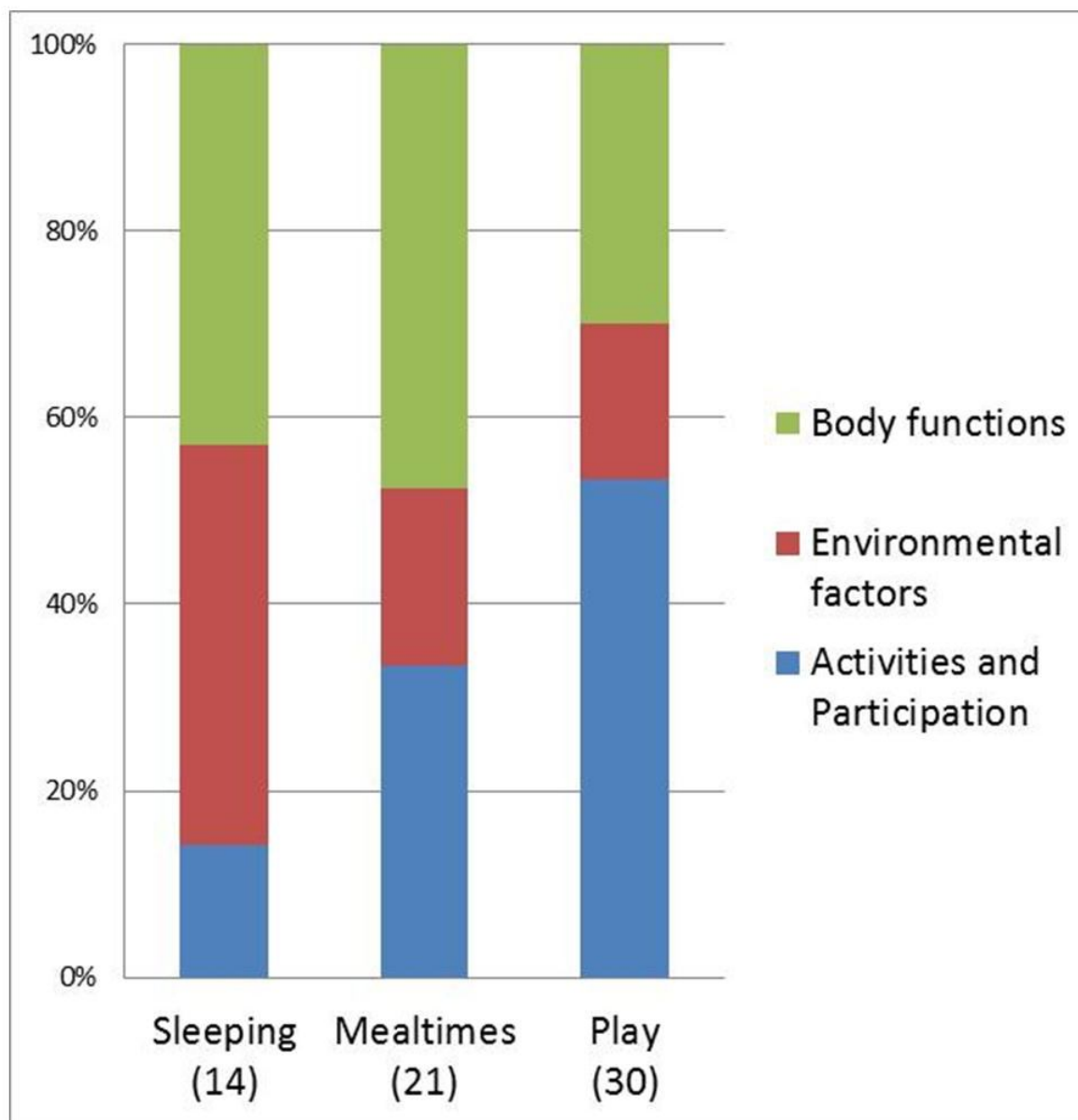
6 families
7 parents – 5 mothers, 2 fathers
13 typically developed children 0-6 yrs



Delphi process



Distribution of codes across components



Environm. Act/Participation

Body Functions

	Prof.	Parents
Exploring objects by mouthing, touching, tasting ,or smelling	X	X
Directing and maintaining attention to specific actions or tasks	X	
Calling for attention and/or express desires by babbling or making other kinds of noise		X
Using gestures, symbols and drawings to communicate and express desires	X	
Maintaining a body position	X	X
Using hands and arms	X	X
Eating and drinking	X	X
Food and drink. E.g. appropriateness, nutrition, amount, consistency	X	X
Products and technology for personal use in daily living	X	
Support and attitudes – immediate family	X	
Support and attitudes - Personal care providers and personal assistants	X	
Energy and drive functions.	X	X
Perceptual functions. E.g. recognize and interpret sensory	X	X
Taste Functions. I.e. sense qualities of bitterness, sweetness, sourness, and saltiness	X	X
Smell functions		X
Hypersensitivity reactions, e.g. allergies, eczemas		X
Functions for eating and drinking.	X	X
Breakdown of food and tolerance to food.	X	X
Defecation		X
Weight maintenance		X
Voluntary movements , i.e. coordination and control	X	
Involuntary movement	X	

Most important ICF-CY categories

Sleeping

b124 Sleep functions

d410 Changing body positions

e310-e410 Support and attitudes from immediate family

Mealtimes

b510 Functions for eating and drinking

d120 Purposeful sensing

d415 Maintaining body position

d550-d560 Eating and drinking

Play

d120 Purposeful sensing

d131 Learning through play

d710 Interacting with people

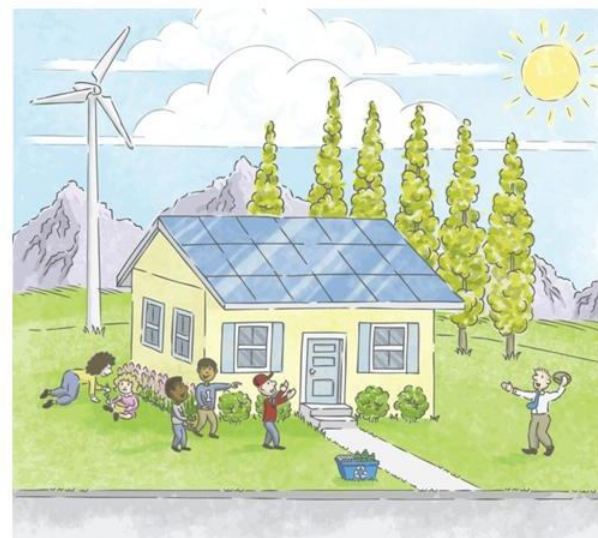
e310, e410 Support or attitudes from immediate family

ICF-CY categories included in all three code sets

Enironmental factors

e310 Support from immediate family

e410 Individual attitudes of immediate family members



Code set Sleeping 0-6 years



Sara can not sleep

Why?

• **d230**

Carrying out daily routines.
E.g. undress, going to bed,
getting up in the morning,

• **d410**

Changing body position.
E.g. lie down on the bed, rise
up, roll from one side to the
other

• **e110**

Drugs.
E.g. kind and amount
of medication

• **e115**

Equipment for daily
activities.
E.g. bedding

• **e225** Climate.

E.g. temperature

• **e240**

Light. E.g. sun light,
illumination

• **e250**

Sound. E.g. volume,
background noise

• **e310** Support from
immediate family

• **b134**

Sleep functions, i.e. to fall asleep and maintain
sleeping

• **b152**

Emotional functions, E.g. sadness, happiness,
fear, anger, tension

• **b460**

Sensations associated with cardiovascular and
respiratory functions such as tightness of
chest, irregular heart beat, palpitation,
wheezing, air hunger

• **b525**

Defecation functions. E.g. flatulence

• **b735**

Muscle tone, functions. E.g. hypertonia and
muscle spasticity

• **b761**

Spontaneous movements such as in infancy

Activities and
Participation (2)

Environmental
factors (6)

Body functions (6)

Next step



Listen to children!

Focus groups

- what is important in daily life
 - how to name EDLS
 - what would improve functioning and participation in situations that are not satisfactory
-

TACK!



Thanks!

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Thanks!

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- Adolfsson, M., Granlund, M. & Pless, M. (2012). Professionals' views of children's everyday life situations and the relation to participation. *Disability and Rehabilitation*, 34 (7) , 581-592
- Adolfsson, M. (2012 Early online) Applying the ICF-CY to Identify Children's Everyday Life Situations: A step towards participation-focused code sets. *International Journal of Social Welfare*
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Code set Mealtimes 0-6 years

Little Peter can not participate properly in family meals

WHY?

- **d120**
Exploring objects by mouthing, touching, tasting ,or smelling
- **d161**
Maintaining attention
- **d331**
Calling for attention
- **d335**
Express desires
- **d415**
Maintaining a body position
- **d440-445**
Using hands and arms
- **d550-560**
Coordinate tasks and actions of eating food and drinking

Activities and Participation (7)

- **e110**
Access to appropriate food
- **e115**
Access to appropriate utensils for eating
- **e310+e410**
Support and attitudes from immediate family
- **e340+e440**
Support and attitudes from personal care providers and personal assistants

Environment (4)

- **b130**
Energy and drive functions
- **b156**
Perceptual functions
- **b250-b255**
Taste and smell functions
- **b435**
Hypersensitivity reactions
- **b510**
Functions for eating and drinking. E.g. sucking, biting, chewing, manipulation of food in the mouth, salivation, swallowing
- **b515**
Breakdown of food and tolerance to food
- **b525**
Defecation
- **b530**
Weight maintenance
- **b760-b765**
Voluntary and involuntary movement

Body functions (9)



Code set Play 0-6 years

John and Emma are not playing as other children

Why?

- **d110- d115** Watching and listening
- **d120** Experience stimuli such as touching, tasting and smelling
- **d131** Learning through play and to actions with objects
- **d161** Focusing attention
- **d177** Making decisions, making choices
- **d210** Carrying out tasks and
- **d315-d320, d330, d335** Communicating, comprehending meanings of messages, using sign language, speaking and telling stories
- **d415** Maintaining body positions
- **d440-d445** Using hands and arms
- **d571** Avoiding risks
- **d710** Interacting with people
- **d720** Maintaining interactions
- **d815** Preschool education
- **d880** Engaging in play

Activities and
Participation (16)

- **e115**
Equipment/product
s used for play
- **e120**
Equipment/product
s used for mobility
- **e125**
Equipment/product
sused for
communication
- **e310+e410**
Support and
attitudes from
immediate family
- **e340+e440**
Support and
attitudes from
personal care
providers and
personal assistants

Environmental
factors (5)

- **b110**
Consciousness functions
- **b125**
Activity level
- **b140** Attention functions
- **b152**
Emotional functions
- **b156**
Perceptual functions
- **b160**
Thought functions
- **b260**
Proprioceptive functions
- **b760-b765**
Control of voluntary and
involuntary movement
functions

Body functions (8)

Conclusion

Sleeping, Mealtimes and Play

- ➡ The views of parents and professionals are not consistent
- ➡ Immediate family is essential for child functioning
- ➡ Code sets would support dialogues about child participation
- ➡ Delphi technique is useable
- ➡ Content in code sets differ

