Everyday life situations of young children

Margareta Adolfsson
Physiotherapist, PhD in disability science

margareta.adolfsson@hlk.hj.se
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

- Social worker
- Physician
- Psychologist
- Nurse
- Speech/language therapist
- Dietician
- Special educator
- Occupational therapist
- Physiotherapist
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

<table>
<thead>
<tr>
<th><strong>Long-term goal</strong></th>
<th><strong>Missing</strong></th>
<th><strong>Aim of study</strong></th>
</tr>
</thead>
</table>
| Opportunities for children with disabilities and their parents to express opinions and take part of professional knowledge during intervention processes | Structured model to assess child participation in everyday life situations | 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 |

Interdisciplinary screening tool
ICF-CY
International Classification of Functioning, disability and health, version for Children and Youth

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 Individual Child’s Fun in Certain Years
!?!?!
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”

Adolfsson, M., Granlund, M., Björck-Åkesson, E., Ibragimova, N. & Pless, M. (2010). Exploring changes over time in habilitation professionals' perceptions and applications of the ICF-CY. J of Rehabilitation Medicine. 42(7); 670-678
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)


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

- Sleeping
- Mealtimes
- Play
## Mapping items in to ICF-CY codes

<table>
<thead>
<tr>
<th>Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telling stories</td>
</tr>
<tr>
<td>Singing</td>
</tr>
<tr>
<td>Having a conversation</td>
</tr>
<tr>
<td>Riding a bike</td>
</tr>
<tr>
<td>Cutting and pasting</td>
</tr>
<tr>
<td>Going to the spaza shop</td>
</tr>
<tr>
<td>Visiting shopping malls</td>
</tr>
<tr>
<td>Playing arcade games</td>
</tr>
<tr>
<td>Mokuku</td>
</tr>
<tr>
<td>Eating out</td>
</tr>
<tr>
<td>Hair cut/style</td>
</tr>
</tbody>
</table>


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

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

- Communication
- Selfcare
- Family relations
- Play

Younger (0-6 yrs); 4 data sets included
Older (7-17 yrs); 5 data sets included
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

Initial list of **145** ICF-CY codes

Round 1-3

- Sleeping **14**
- Mealtimes **21**
- Play **30**
Distribution of codes across components

- **Sleeping (14)**
  - Body functions: 40%
  - Environmental factors: 20%
  - Activities and Participation: 40%

- **Mealtimes (21)**
  - Body functions: 30%
  - Environmental factors: 30%
  - Activities and Participation: 40%

- **Play (30)**
  - Body functions: 60%
  - Environmental factors: 20%
  - Activities and Participation: 20%
<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
<th>Prof.</th>
<th>Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Act/Participation</td>
<td>Exploring objects by mouthing, touching, tasting, or smelling</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Directing and maintaining attention to specific actions or tasks</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Calling for attention and/or express desires by babbling or making other</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>kinds of noise</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Using gestures, symbols and drawings to communicate and express desires</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Maintaining a body position</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Using hands and arms</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Eating and drinking</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Environment</td>
<td>Food and drink. E.g. appropriateness, nutrition, amount, consistency</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Products and technology for personal use in daily living</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Support and attitudes - immediate family</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Support and attitudes - Personal care providers and personal assistants</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Body Functions</td>
<td>Energy and drive functions</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Perceptual functions. E.g. recognize and interpret sensory</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Taste Functions. I.e. sense qualities of bitterness, sweetness, sourness,</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>and saltiness</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Smell functions</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Hypersensitivity reactions, e.g. allergies, eczemas</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Functions for eating and drinking</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Breakdown of food and tolerance to food.</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Defecation</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Weight maintenance</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td></td>
<td>Voluntary movements, i.e. coordination and control</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Involuntary movement</td>
<td>x</td>
<td></td>
</tr>
</tbody>
</table>
## Most important ICF-CY categories

<table>
<thead>
<tr>
<th>Sleeping</th>
<th>Mealtimes</th>
<th>Play</th>
</tr>
</thead>
<tbody>
<tr>
<td>b124 Sleep functions</td>
<td>b510 Functions for eating and drinking</td>
<td>d120 Purposeful sensing</td>
</tr>
<tr>
<td>d410 Changing body positions</td>
<td>d120 Purposeful sensing</td>
<td>d131 Learning through play</td>
</tr>
<tr>
<td></td>
<td>d415 Maintaining body position</td>
<td>d710 Interacting with people</td>
</tr>
<tr>
<td></td>
<td>d550-d560 Eating and drinking</td>
<td></td>
</tr>
<tr>
<td>e310-e410 Support and attitudes from</td>
<td>e310, e410 Support or attitudes from immediate family</td>
<td></td>
</tr>
</tbody>
</table>
ICF-CY categories included in all three code sets

Environmental factors

e310 Support from immediate family

e410 Individual attitudes of immediate family members
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 chess, 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!

CHILD

Thanks!

margareta.adolfsson@hlk.hj.se
Thanks!


margareta.adolfsson@hlk.hj.se
**Code set Mealtimes 0-6 years**

**Little Peter can not participate properly in family meals**

**WHY?**

<table>
<thead>
<tr>
<th>Activities and Participation (7)</th>
<th>Environment (4)</th>
<th>Body functions (9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• <strong>d120</strong> Exploring objects by mouthing, touching, tasting, or smelling</td>
<td>• <strong>e110</strong> Access to appropriate food</td>
<td>• <strong>b130</strong> Energy and drive functions</td>
</tr>
<tr>
<td>• <strong>d161</strong> Maintaining attention</td>
<td>• <strong>e115</strong> Access to appropriate utensils for eating</td>
<td>• <strong>b156</strong> Perceptual functions</td>
</tr>
<tr>
<td>• <strong>d331</strong> Calling for attention</td>
<td>• <strong>e310</strong> Support and attitudes from immediate family</td>
<td>• <strong>b250</strong> Taste and smell functions</td>
</tr>
<tr>
<td>• <strong>d335</strong> Express desires</td>
<td>• <strong>e340</strong> Support and attitudes from personal care providers and personal assistants</td>
<td>• <strong>b255</strong> Taste and smell functions</td>
</tr>
<tr>
<td>• <strong>d415</strong> Maintaining a body position</td>
<td>• <strong>b435</strong> Hypersensitivity reactions</td>
<td>• <strong>b445</strong> Taste and smell functions</td>
</tr>
<tr>
<td>• <strong>d440-445</strong> Using hands and arms</td>
<td>• <strong>b510</strong> Functions for eating and drinking. E.g. sucking, biting, chewing, manipulation of food in the mouth, salivation, swallowing</td>
<td>• <strong>b515</strong> Breakdown of food and tolerance to food</td>
</tr>
<tr>
<td>• <strong>d550-560</strong> Coordinate tasks and actions of eating food and drinking</td>
<td>• <strong>b525</strong> Defecation</td>
<td>• <strong>b530</strong> Weight maintenance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• <strong>b760</strong> Voluntary and involuntary movement</td>
</tr>
</tbody>
</table>
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

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

Activities and Participation (16)
Environmental factors (5)
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

Adolfsson, Björck-Åkesson, & Lim. (Accepted). Code sets for everyday life situations of children aged 0-6: Sleeping, mealtimes, and play. A pilot study based on the ICF-CY. *British Journal of Occupational Therapy*