




ICF-CY
to understand everyday life situations for children and youth.
Assessments instruments for collaborative problem solving
in child- and youth habilitation

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ICF-CY
enhance focus on participation and environment

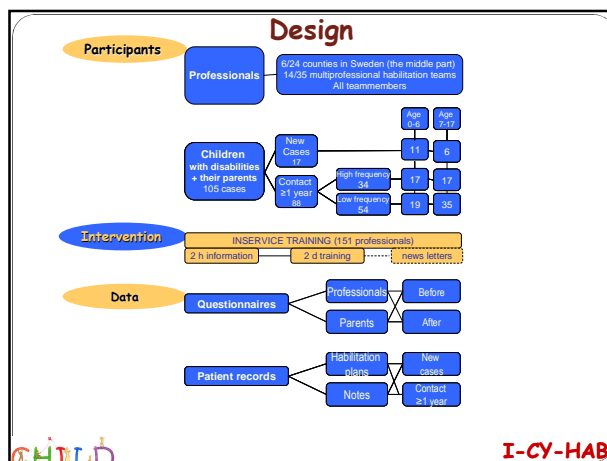
"The ICF-CY helps us to raise our eyes and see what is most important for each child"

I-CY-HAB project (2005-2009)
Eva Björk-Åkesson, Mats Granlund, Mia Pless, Nina Ibragimova, Margareta Adolfsson

Evaluation of in-service training in Östergötland (2008)
Margareta Adolfsson, Mats Granlund

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*Utility and feasibility of ICF-CY in
early intervention/habilitation settings for children*



Knowledge, understanding and use of the ICF-model - professionals

- What do professionals **know** about ICF, ICF-CY och ICIDH?
- How easily can they **understand** the components of the model?
- What components do they **use** in assessment?

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Results – knowledge about the model
Before and 1 year after ICF/ ICF-CY in-service training
Pless et al. (2009) Evaluation of in-service training in using the ICF-CY

	BEFORE		AFTER		Difference Sign. (Yes)
	M (SD) Range	M (SD) Range	M (SD) Range	M (SD) Range	
ICF	0.94 (.55) 0-3	1.20 (.60) 0-3			.000
ICF-CY	0.68 (.56) 0-2	1.33 (.61) 0-3			.000
ICIDH	0.68 (.66) 0-3	0.96 (.72) 0-3			.000

Categories

- "Participate and use" (n = 81)
 - ☐ ICF 1.10 - 1.39
 - ☐ ICF-CY 0.70 - 1.58
- "Participate" (n = 32)
 - ☐ ICF 0.84 - 0.91
 - ☐ ICF-CY 0.59 - 1.13

0-1 = None/limited knowledge, 2-3 = Use sometimes or often in clinics

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Results— understanding components (BEFORE - AFTER)

LOW = "Not at all or to some extent"; HIGH = "Quite or very easy"
 Pless et al. (2009) Evaluation of inservice training in using the ICF-CY

Statements (components)	"Participated and Used" GroupMean	"Participated" GroupMean
She can not handle stress (bf)	LOW - HIGH	LOW - LOW
She easily loose attention" (bf)	LOW - HIGH	LOW - LOW
He can control his bladder (bf)	LOW - HIGH	LOW - LOW
She has a deformed eye (bs)	HIGH - HIGH	LOW - HIGH
His back is crooked (bs)	HIGH - HIGH	LOW - LOW
His hip is dislocated (bs)	HIGH - HIGH	LOW - LOW
He can't ride a bike" (a)	LOW - HIGH	LOW - LOW
Train Lisa to write her name (a)	LOW - HIGH	LOW - LOW
He can not speak (a)	LOW - HIGH	LOW - LOW
She chooses to play football with her friends (p)	HIGH - HIGH	LOW - LOW
He likes to interact in play (p)	LOW - HIGH	LOW - LOW
He wants to go to cinema with his assistant (p)	HIGH - HIGH	LOW - LOW
Take away doorsteps (e)	HIGH - HIGH	LOW - LOW
"Wheelchair is to small" (e)	LOW - HIGH	LOW - LOW
Instruct the staff about Carl's play (e)	HIGH - HIGH	LOW - LOW

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Results – use of components in assessment

(BEFORE - AFTER)

LOW = "Not at all or sometimes"; HIGH = "Quite often or very often"

Components for assessment	"Participated and Used" (n = 81)	"Participated" (n = 32)
How the child function psychologically (bf)	HIGH - HIGH	HIGH - HIGH
How the chil'd body functions (bf)	LOW - LOW	LOW - LOW
The child's organs (bs)	LOW - LOW	LOW - LOW
What activities the children can perform (a)	HIGH - HIGH	HIGH - LOW
What the children can do in their natural environment (a)	HIGH - HIGH	HIGH - LOW
What children do on their own initiative (p)	HIGH - HIGH	HIGH - HIGH
The children's intercation with friends (p)	HIGH - HIGH	HIGH - HIGH
The child's physical environment (e)	LOW - LOW	LOW - LOW
Support and attitudes in the children's environment (e)	HIGH - HIGH	HIGH - HIGH

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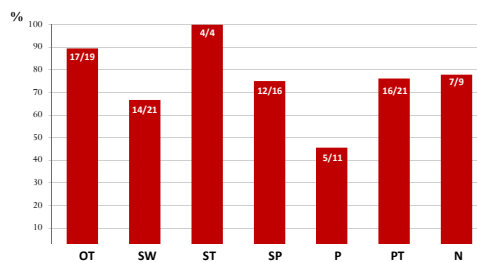
Summary

- Knowledge, understanding and use of the ICF-model
- professionals in habilitation services perceive it as low
- increase when they participate in in-service training and use what they have learnt
- ICF-model is feasilben in habilitation services
- professionals use all components in the model, that is, those who both participate in in-service training and use what they have learnt

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To what degree is the ICF-CY used?

(Users/Participants)



OT-occupational therapist, SW-social worker, ST-speech therapist, SP-special pedagogue, P-psychologist, PT-physical therapist, N-nurse

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Use of the ICF-CY

- 3 categories
- Habilitation process
 - Teamwork
 - Thoughts



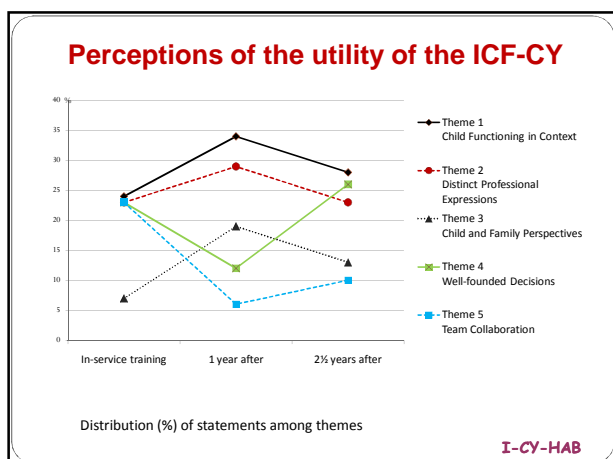
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Perceptions of the use of ICF-CY

- 5 themes
- Child functioning in context
 - Distinct professional expressions
 - Child and family perspectives
 - Well-founded decisions
 - Team collaboration



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Applications of the ICF-CY

2 levels

- Individual**
 - assessment
 - habilitation planning
 - evaluation
- Organizational**
 - information
 - documentation
 - materials

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Introduction of the ICF-CY

A long term project

- Time
- Planning
- Support
- Adaptations
- Everyday use and feed back
- Engagement

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I-CY-HAB Forms

Common assessment tool for use in clinical work

The aim is to give support for

- Describing life situations
- Clarifying requirements
- Planning interventions
- Prioritizing interventions

The forms are NOT measures!

Form 1 – Activities/Participation Performance
What the child does in daily life situations

Capacity
What the child can do better under other circumstances

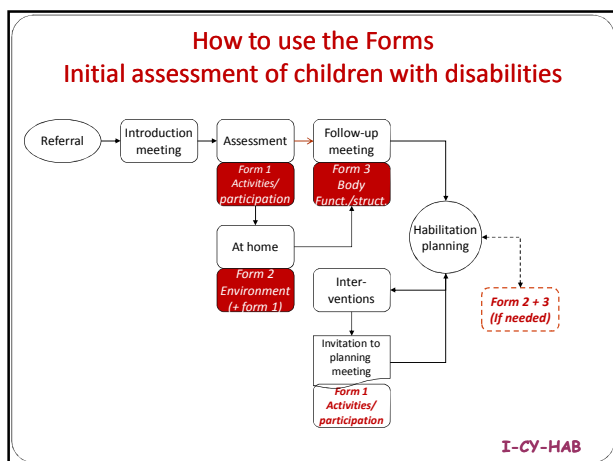
Participation/Wishes
What the child want to do better

Form 2 – Environmental factors
What helps, what hinders?

Form 3 – Body functions / structures
Strengths and weaknesses!

Problem solving matrix

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How your child learns new things, uses what she/he knows and performs different tasks in everyday life and the child's reaction on demand.

Relevant to ask	Has your child experienced difficulties with: (According to situation during the last month)	NO		YES					Can do better	Comments	Would like to do better
		How large are the difficulties?									
		Just a little	A moderate level	A lot	Can not do at all	Unknown level					
d1 – LEARNING AND APPLYING KNOWLEDGE											
d120	To explore objects by mouthing, touching, tasting or smelling	1	2	3	4						
d131	To play with things and learn through play I.e. stir with a spoon, put on a lid, pretend that a piece of wood is a car, roll a ball.	1	2	3	4						
d2 – GENERAL TASKS AND DEMANDS											
d210	To perform a single task or responding to a single command. I.e. put on a sock, do homework, sort objects, play hide and seek with friends, or take one instruction.	1	2	3	4						
											Does your child have the capacity to do this better in other situations?
What areas does the child/youth want to function better in or participate more in?											

Important products and technical equipment that your child needs.

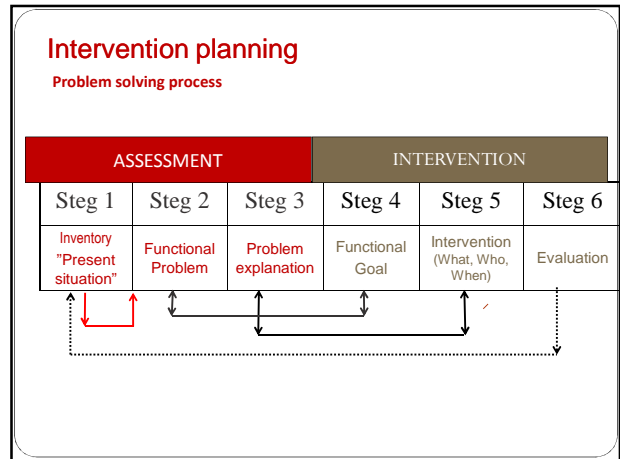
Is your child's life affected by these factors in a positive way (facilitator) or in a negative way (barrier)?	YES - Facilitator										YES - Barrier										Intervention needed	Comments
	Extent of help?										Extent of hinder?											
	Mid	Moderate	Substantial	Complete	Unknown level	Slight	Moderate	Severe	Complete	Unknown level	Slight	Moderate	Severe	Complete	Unknown level							
e1 - PRODUCTS AND TECHNOLOGY																						
e1110	Food and drink. For example appropriateness, nutrition, amount and consistency																					
e1101	Drugs. For example type of drug, amount for medical purposes																					
e115	Products and technology for personal use in daily living. For example furniture, stroller, chairs, personal care equipment, adapted or specially designed devices, and orthopedic devices.																					
If some of those factors are barriers for your child's well-being - Would you like an intervention now?																						

BODY FUNCTIONS - EXAMPLES

Relevant to ask	Has your child problems with: (In relation to a child at the same age)	Yes										Can be improved	Comments									
		Extent of problems?																				
		Slight	Moderate	Severe	Complete	Unknown level	Slight	Moderate	Severe	Complete	Unknown level											
b1 - MENTAL FUNCTIONS																						
b114	Orientation, i.e. to time, place and person. For example, the child is aware of "today," "tomorrow," location of its own identity or the identity of other individuals in the immediate environment.																					
b163	Basic cognitive functions. For example, knowing and reasoning, carrying out tasks demanding understanding of how situations work out.																					
b4 - FUNCTIONS OF THE CARDIOVASCULAR, HAEMATOLOGICAL, IMMUNOLOGICAL AND RESPIRATORY SYSTEMS																						
b460	Sensations associated with cardiovascular and respiratory functions. For example, sensations of tightness of chest, feelings of irregular beat, dyspnoea, air hunger, choking, gagging and wheezing																					
Do you as a parent - in collaboration with habilitation professionals - estimate that any function can be improved now?																						

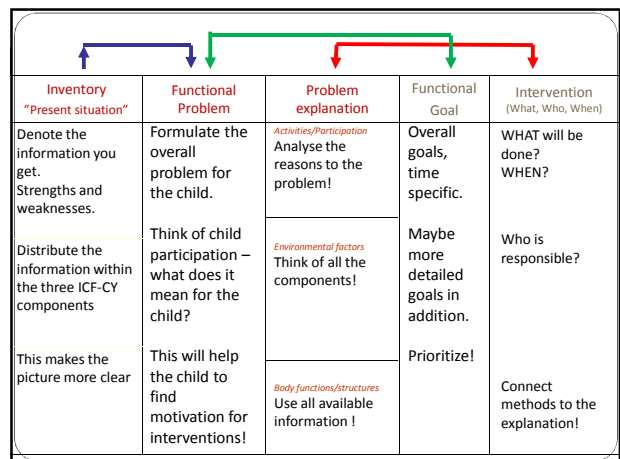
Structure and development of the child's body, i.e. anatomical parts such as organs, limbs and their components.
It is about significant deviation or loss that can be seen with the naked eye, or has been established by X-ray or other examinations.

Relevant to ask	Has your child deviations related to: (in relation to a child at the same age)	Yes										Can be improved	Comments									
		Extent of deviations?																				
		Slight	Moderate	Severe	Complete	Unknown level	Slight	Moderate	Severe	Complete	Unknown level											
b1 - MENTAL FUNCTIONS																						
s1	Nervous system. For example brain, spinal cord or nerves																					
s2	Eyes. For example eyeball, cornea, iris, retina, lachrymal gland, eyelid, eyebrow, external ocular muscles																					
s7	Structures related to movement. For example skeleton with vertebrae and other bones, muscles, joints, ligaments																					
Do you as a parent - in collaboration with habilitation professionals - estimate that any function or deviation can be improved or compensated now?																						



ICF-CY A model for thinking - focus on participation

FUNCTIONAL PROBLEM	PROBLEM EXPLANATION
Activities/Participation Emma cannot independently wash her hands	Emma cannot wash herself standing
Environmental factors The wash-basin is too high up	The wash-basin is too high up The wheel chair cannot come close to the wash-basin
Body functions / structures	Emma's muscle power is impaired



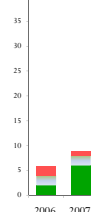
Content in the I-CY-HAB Forms



One year after in-service training (2007)
An excellent tool. Overall another focus on the needs for interventions

...complicated, but I realize the utility of the forms since they include many perspectives.

Questions about environmental factors provide new perspectives



I-CY-HAB

Content in the I-CY-HAB Forms



During in-service training (2006)
Problem-focused. I prefer to highlight strengths and develop them

One year after (2007)
The main part of my work as a psychologist is not included



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Design of the I-CY-HAB Forms



During in-service training:
Could be useful, but they are too comprehensive as they are now
Comprehensive forms. How will parents be able to complete them? Lots of text!

One year after:
Disadvantages that the material is quite challenging to learn and thus becomes difficult to use fully without adjustments



I-CY-HAB

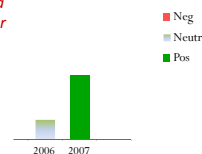
Utility of the I-CY-HAB Forms

During in-service training:
The matrix is useful for habilitation planning – to see how things go together.
Provides categories thought out by others, not threatful.

One year after:
Converse way of thinking, asking questions in a new way, focus on participation. Provides other answers.

Important, useful tool, facilitates assessment to highlight the needs of support and interventions .

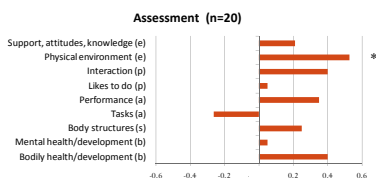
During habilitation planning, the goals will be more exact



I-CY-HAB

Before - after training and use of the forms

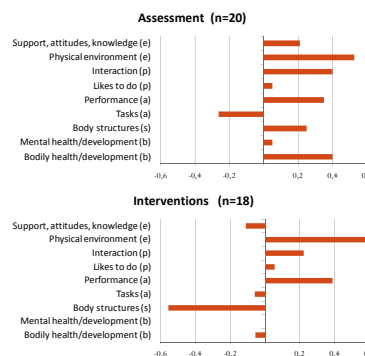
(In-service training in Östergötland)



Dependent t-test
* Sign differences

Before - after training and use of the forms

(In-service training in Östergötland)




Dependent t-test
* Sign differences

Statements on the Forms

(In-service training in Östergötland)

Comprehensive! Time consuming



Benefits

- Parents like it
- Gives a lot of information. More areas than before
- Environmental factors explain functioning
- Parents delivered suggestions
- Interesting discussions
- Education/redefinition for parents. Look upon problems differently

Drawbacks

- Difficult for prof. to prioritize most important caegories
- Difficult questions for parents

Core sets and 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

Stucki et al. (2002). Application of the International Classification of Functioning, Disability and Health (ICF) in clinical practice
Simeonsson et al. (2009). Developmental and health assessment in rehabilitation with the ICF for Children and Youth.

ICF/ICF-CY Core sets

Condition specific core-sets

Aim
To link specific conditions or diseases to all important ICF categories of functioning, not only body functions and structures.

Core sets available or in progress
12 available for adults, e.g. low back pain, depression, stroke, RA, chronic pain, osteoporosis, osteoarthritis, chronic heart disease
For children: Hearing is in progress, severe disabilities, CP

ICF/ICF-CY Code sets

Code sets across health conditions


Aim
To define and profile nature of functioning and disability and highlight individual differences
To define eligibility or to match children's needs to services and supports

Code sets in progress
Age groups, life areas (e.g. communication), everyday life situations (e.g. sleep, mealtimes, play), school settings, service settings (e.g. ECI, ECE, mental health, vocational rehab)

Everyday life situation - mealtime

Peter can not participate in meals (p)

WHY?



<p>Activities/ participation</p> <ul style="list-style-type: none"> • d155 Acquiring basic skills • d177 Making decisions • d2102 Undertaking a single task • d2305 Managing one's time • d4153 Maintaining a sitting position • d4401 Grasping • d5701 Managing diet and fitness • d7203 interacting according to social roles 	<p>Environment</p> <ul style="list-style-type: none"> • e1100 Food (e.g. consistencies) • e115 Products for personal use in daily living (e.g. fork and spoon, chair) • e3 Support • e4 Attitudes 	<p>Body</p> <ul style="list-style-type: none"> • b1302 Appetite • b140 Attention • b1563 Gustatory perception • b1641 Organizing and planning • b510 Ingestion functions • b515 Digestive functions • b730 Muscle power • b735 Muscle tone • b740 Muscle endurance • s320-340 Structure of mouth, pharynx, and larynx • s5 Digestive system
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Three steps to identify everyday life situations common for children

1. Systematic literature search – existing measures of performance or participation. Mapping items to ICF-CY
2. Professional view - Concurrent data collect
 - open-ended question
 - questionnaire on ICF-CY categories
3. Triangulation with other studies to catch children's and parent's perspectives

Mapping items in measures to ICF-CY codes

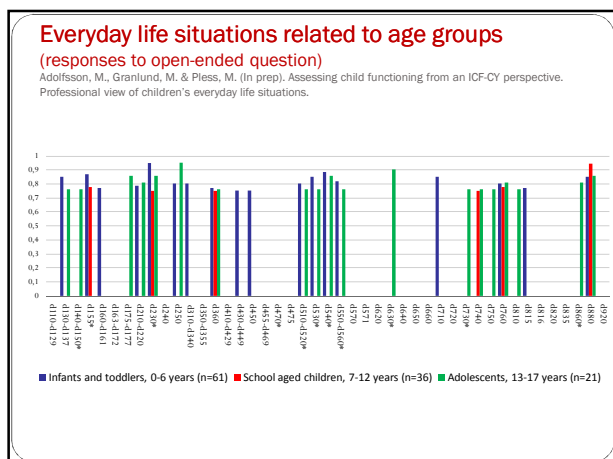
GMFM	COPM	AMPS	ICF code	Category
		X	b130	Energy and drive functions
		X	b164	Higher-level cognitive functions
			b280	Sensation of pain
		X	b735	Muscle tone functions
		X	b760	Control of voluntary movement functions
		X	d177	Making decisions
	X		d360	Using communication devices/techniques
X		X	d450	Walking
X	X	X	d499	Mobility - unspecified
	X		d510	Washing oneself
	X		d540	Dressing
	X		d630	Preparing meals
	X		d920	Recreation and leisure
	-	X	nc	Not covered

GMFM = Gross Motor Function Measure; **COPM** = Canadian Occ. Performance Measure; **AMPS** = Assessment of Motor and Process Skills

3 everyday life situations from 12 measures of performance or participation

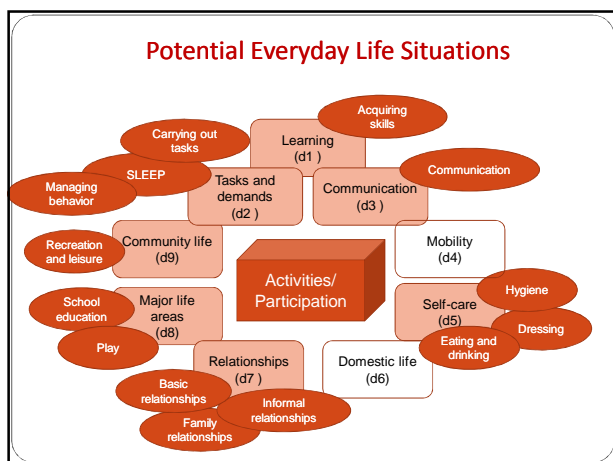
Adolfsson, M., Malmqvist, J., Pless, M., & Granlund, M. (Submitted). Assessing child functioning from an ICF-CY perspective. Everyday life situations explored in measures of performance and participation.

	Infants and Toddlers < 3 years	Preschool- and School-ages 3-12 years	Adolescence 13-18 years	All ages 0-18 years
d1 Learning/ Applying Knowledge				
d2 General Tasks and Demands				
d3 Communication				
d329-d349 Communicating - producing	7%	2%	1%	2%
d4 Mobility				
d410-d429 Changing and maintaining body position	12%	3%	3%	4%
d450-d469 Walking and moving around	15%	9%	9%	10%
d5 Self-care				
d540 Dressing	6%	3%	3%	3%
d550-d560 Eating and Drinking	7%	1%	1%	2%
d6 Domestic Life				
d630-d649 Household tasks	4%	8%	4%	7%
d7 Interspers. Interact. Relationships				
d8 Major Life Areas				
d880 Engagement in play	6%	8%	6%	8%
d9 Community, Social and Civic Life				
d920 Recreation and leisure	4%	31%	47%	29%




14 everyday life situations emerged from the two concurrent data collections

	Open-ended question on life situations	Questionnaire on constructs
Acquiring skills, d155.		x
Carrying out, completing, and sustaining tasks, d210-d220.		x
Carrying out daily routines, incl sleep, d230	x	x
Managing one's own behavior, d250		x
Communication, d3	x	x
Hygiene, d510-530	x	
Dressing, d540		x
Eating and drinking, d550-d560	x	
Basic interpersonal interactions, d710		x
Informal relationships, d750	x	
Family relationships, d760		x
School education, d820	x	
Engagement in play, d880	x	x
Recreation and leisure, d920	x	



Reference – web-based lectures



The Canadian ICF Training Course
<http://www.bcchildrens.ca/professionals/EducationTraining/ICF.htm>

Simonsson. (2009). *ICF-CY (2007) – plus 2 years. Part A.*
<http://breeze.unc.edu/p36151765/>

- Status of the ICF-CY 2 years after publication
- Implementation in policy, research, and practice
- Ongoing and emerging issues likely to be addressed next

Simonsson. (2009). *ICF-CY (2007) – plus 2 years. Part B.*
<http://breeze.unc.edu/icicypartb/>

- The concepts of participation and environmental factors
- The issue of personal factors ("empty box")
- Diagnostic variability and comorbidity in functional documentation
- Linking existing instruments and developing new tools and measures to the ICF-CY



Publications

- Björck-Åkesson, E. & Granlund, M. & Ibragimova, N., (2006). *Svensk fältprövning av WHO:s Internationella klassifikation av funktionstillstånd, funktionshinder och hälsa, version för barn och ungdom (ICF-CY)*. CHILD rapportserie, Nr. 11. ISB. Mälardalens högskola.
- Adolfsson, M., Pless, M., Björck-Åkesson, E., Ibragimova, N. & Granlund, M. (2007). Development of ICF-CY Forms in Sweden. MHADIE. (Unpublished report).
- Adolfsson M, Granlund M. (2008). Återrapportering efter utbildning i ICF/ICF-CY för habiliteringarna i Östergötlands län [Report to the county council of Östergötland]. (Unpublished report).
- Ibragimova, N., Björck-Åkesson, E. & Granlund, M. (2009) Field trial of ICF-CY in Swedish child and youth habilitation services – the structure, developmental issues and clinical use. *Neurodevelopmental rehabilitation*.
- Pless, M., Ibragimova, N., Adolfsson, M., Björck-Åkesson, E. & Granlund, M. (2009). Evaluation of in-service training in using the ICF and ICF version for children and youth. *Journal of Rehabilitation Medicine*.
- Klang, N., Adolfsson, M., Pless, M., Granlund, M. & Björck-Åkesson, E. (in process). Using content analysis when linking information in individual habilitation plans to the ICF-CY.
- Klang, N., Adolfsson, M., Pless, M., Granlund, M. & Björck-Åkesson, E. (in process). Link between assessment and intervention documented in individual habilitation plans.
- Adolfsson, M., Granlund, M., Björck-Åkesson, E., Ibragimova, N. & Pless, M. (2010). Exploring changes over time in habilitation professionals' perceptions and applications of the International Classification of Functioning, Disability and Health, version for Children and Youth (ICF-CY). *J of Rehabilitation Medicine*. 42(7); 670-678