

# Identifying disability in childhood : ICF-CY developmental core sets

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# Overview

- Describe the need for core sets in pediatric and habilitation settings
- Define the concept of “developmental core sets”
- Describe a project to derive developmental core sets for four age groups based on ICF-CY
- Identify potential uses of developmental core sets in practice and research

# Need for core sets in pediatric habilitation

- Core sets consist of a limited number of ICF codes to succinctly define the dimensions of a health condition
- Extensive core sets have been developed in rehabilitation medicine based on the ICF (Stucki et al, 2003)
- These core sets have focused on diagnosed medical conditions with limited utility for pediatric populations
- The developmental nature of child health conditions calls for core sets based on functional characteristics in key domains not etiologies or diagnoses

# Purposes for developmental core sets

- 1. Define key aspects of child functioning essential in child-environment interactions
- 2. Yield profile of individual child functioning
- 3. Provide information with utility for differentiating children's needs for health, habilitation and education services.
- 4. Use core sets as guides in the development of instrument development, data management and surveys

# Proposed developmental core sets

- Different core sets for four age groups:  
< 3 years; 3-6 years; 7-12 years and 13-18 years
- Limited number of ICF-CY codes per core set
- Core sets encompassing essential aspects of adaptation in child-environment interaction (e.g. learning, task demands, communication, environment..)

# Basis for selecting candidate codes for core sets

- Empirical evidence as indicator of developmental health condition
- Sensitivity as indicator for defined age/stage group
- Indicator is readily and reliably observed characteristic among children by parents, care-providers, health professionals, teachers and others involved in services for children

# Features of core elements

- Selected Body Function, Activities/ Participation and Environmental Factors codes
- Focus on characteristics shared across many health conditions, disabilities and disorders of children
- Emphasis on applicability to therapies and health related interventions such as speech, physical, occupational, therapy, social work, psychology...

# Matrix of domains for age core sets

<b>Age/ domain</b>	<b>&lt;3</b>	<b>3-6</b>	<b>7-12</b>	<b>13-18</b>
<b>Sensory functions</b>				
<b>Learning</b>				
<b>Communication</b>				
<b>Mobility</b>				
<b>Behavior</b>				
<b>Social interaction</b>				
<b>Major life area</b>				
<b>Environment</b>				

# Example of candidates codes for core sets: body function

**b110** Alert/awake

**b120** Thinking

**b134** Sleep

**b140** Paying attention

**b144** Remembering/recalling

**b147** Psychomotor control?

**b156** Recognising sounds, shapes or smells?

**b210** Seeing

**b230** Hearing

**b280** Feeling pain

**b3** Making sounds/ saying words?

# Example of candidate codes for core sets: body functions

**b410** heart functions

**b435** immune defenses, allergies

**b440** Breathing

**b510** Eating

**b515** Digesting food

**b525** Defecating

**b540** General metabolic and endocrine functions ?

**b620** Urinating/wetting?

# Example of candidate codes for core sets: body functions

**b710** Moving wrists, elbows, shoulders or knee joints?

**b730** Muscles weakness

**b735** Muscle tone

**b750** Muscle reflexes

**b760** Coordinating muscle movements

**b765** Tics, tremors/ involuntary movements

**b8. FUNCTIONS OF THE SKIN AND RELATED STRUCTURES**

# Project approach

- 3-round Delphi approach used to seek consensus among professionals on essential codes for core sets
- Scientific and ethical procedures approved by the Institutional Review Board of the University of North Carolina at Chapel Hill
- Potential ICF-CY codes drawn from two sources (a) codes in Annex (minimal set) and (b) identified on the basis of literature review
- Potential codes prepared in separate lists for each age group (<3; 3-6; 7-12; 13-18)

# Project approach: round I

- ICF-CY codes presented in Likert scale format for participants to rate their appropriateness (1-not at all to 5- essential) for inclusion in age-group core sets
- Lists of potential codes for age-group core sets distributed to professionals for completion and return
- Participants encouraged to add codes not on lists and rate their appropriateness for core sets

# Project approach: round II

- Returned forms analyzed and new lists derived for each age group retaining codes given ratings of 4 or 5 by 30% of participants as well as adding any new code recommended by participants
- Derived lists returned to participants for second round of ratings for inclusion in core set for each age group

# Project approach: round III

- Returned forms analyzed and next version of lists derived for each age group retaining codes given ratings of 4 or 5 by >50% of participants
- Derived lists returned to participants for third round of ratings for inclusion in core set for each age group

# Analysis of data

- Returned forms from round III analyzed and codes given ratings of 4 or 5 by >70% of participants retained for inclusion in core sets
- The retained codes constituted items to be listed in final version of core sets for each age group
- Age-group core sets prepared in formats to facilitate use in clinical and research applications

# Proposed Matrix of items by domains for age core sets

Age/ domain	<3	3-6	7-12	13-18
<b>Sensory functions</b>				
Seeing	X	X	X	X
Hearing	X	X	X	X
Pain	X	X	X	X
<b>Learning</b>				
Learning through actions/play	X	X		
Learning academic skills			X	X
Learning concepts		X	X	X

# Proposed Matrix of items by domains for age core sets

Age/ domain	<3	3-6	7-12	13-18
<b>Communication</b>				
Understanding others	X	X	X	X
Speaking		X	X	X
Other communication	X	X		
<b>Mobility</b>				
Using hands, fingers	X	X	X	X
Moving in environment	X	X		
Walking		X	X	X

# Proposed Matrix of items by domains for age core sets

Age/ domain	<3	3-6	7-12	13-18
<b>Behavior-</b>				
Self care		X	X	X
Avoid harm to self	X	X	X	
Independence	X	X	X	X
<b>Social interaction</b>				
Formal relationships		X	X	X
Informal relationships		X	X	X
Family relationships	X	X	X	X

# Proposed Matrix of items by domains for age core sets

Age/ domain	<3	3-6	7-12	13-18
<b>Major life</b>				
Playing alone/others	X	X	X	
Schooling		X	X	X
Using money			X	X
<b>Environment</b>				
Products or substances	X	X	X	X
Building design		X	X	X
Support & relationships	X	X	X	X

# Summary

- Age based core sets of essential codes for children may be useful in:
- The design of screening and assessment instruments
- The selection of variables for data sets
- The identification of variables for surveys
- The basis for description of participants in research studies