

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

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

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
Sensory functions				
Seeing	X	X	X	X
Hearing	X	X	X	X
Pain	X	X	X	X
Learning				
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
Communication				
Understanding others	X	X	X	X
Speaking		X	X	X
Other communication	X	X		
Mobility				
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
Behavior-				
Self care		X	X	X
Avoid harm to self	X	X	X	
Independence	X	X	X	X
Social interaction				
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
Major life				
Playing alone/others	X	X	X	
Schooling		X	X	X
Using money			X	X
Environment				
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