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International Classification of Functioning, Disability and Health: a version for children & youth

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Purpose of presentation

- Identify the issues in documentation of disability in childhood
- Review the International Classification of Functioning, Disability and Health-ICF
- Describe activities to develop a version of the ICF for children and youth
- Identify implications for use of ICF as common language for data on child health, functioning and disability

UN Convention on the Rights of the Child: Article 23, Par. 1

- “States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life in conditions which ensure dignity, promotes self reliance and facilitates the child’s active participation in the community”

UN Convention on the Rights of the Child: Article 23, Par. 2

- “States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child’s condition and to the circumstances of the parents or others caring for the child”.

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- Naming and classification of disability:
how to describe this child?



Contemporary naming and classification of disability in children and youth

- child with severe mental retardation
- child with Williams, Down, Fragile-X, Turner or Rett syndrome
- child with autism-spectrum disorder
- child with communication disorders
- language-disordered child
- child with multiple disabilities

Naming & classification of disability: current issues

- Competing uses in naming and classification
 - **Syndromes:** advances in mapping human genome
 - **Administrative categories:** education and human service systems
 - **Diagnoses:** health and mental health settings
- Inconsistent and arbitrary language of disability is incompatible with effective documentation
- Difficulties aggregating & comparing data
 - across agencies/systems
 - internationally

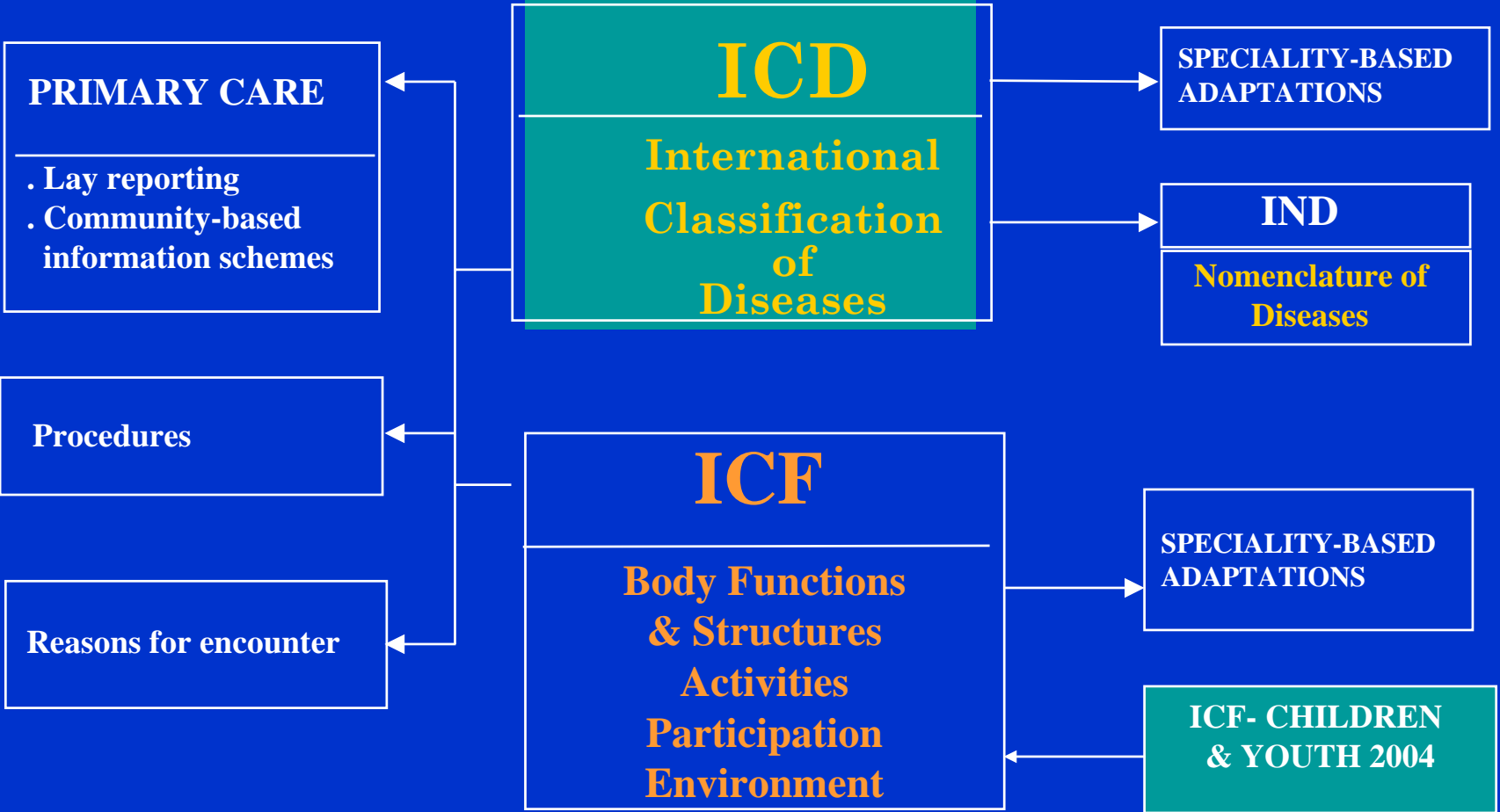
Naming & classification of disability: current issues

- Current classifications are idiosyncratic to disciplines complicating inter-disciplinary coordination
- Need for common, universal language of disability in children and youth(IOM, 2001)
- Contribution of WHO International Classification of Functioning, Disability and Health for documentation of disability

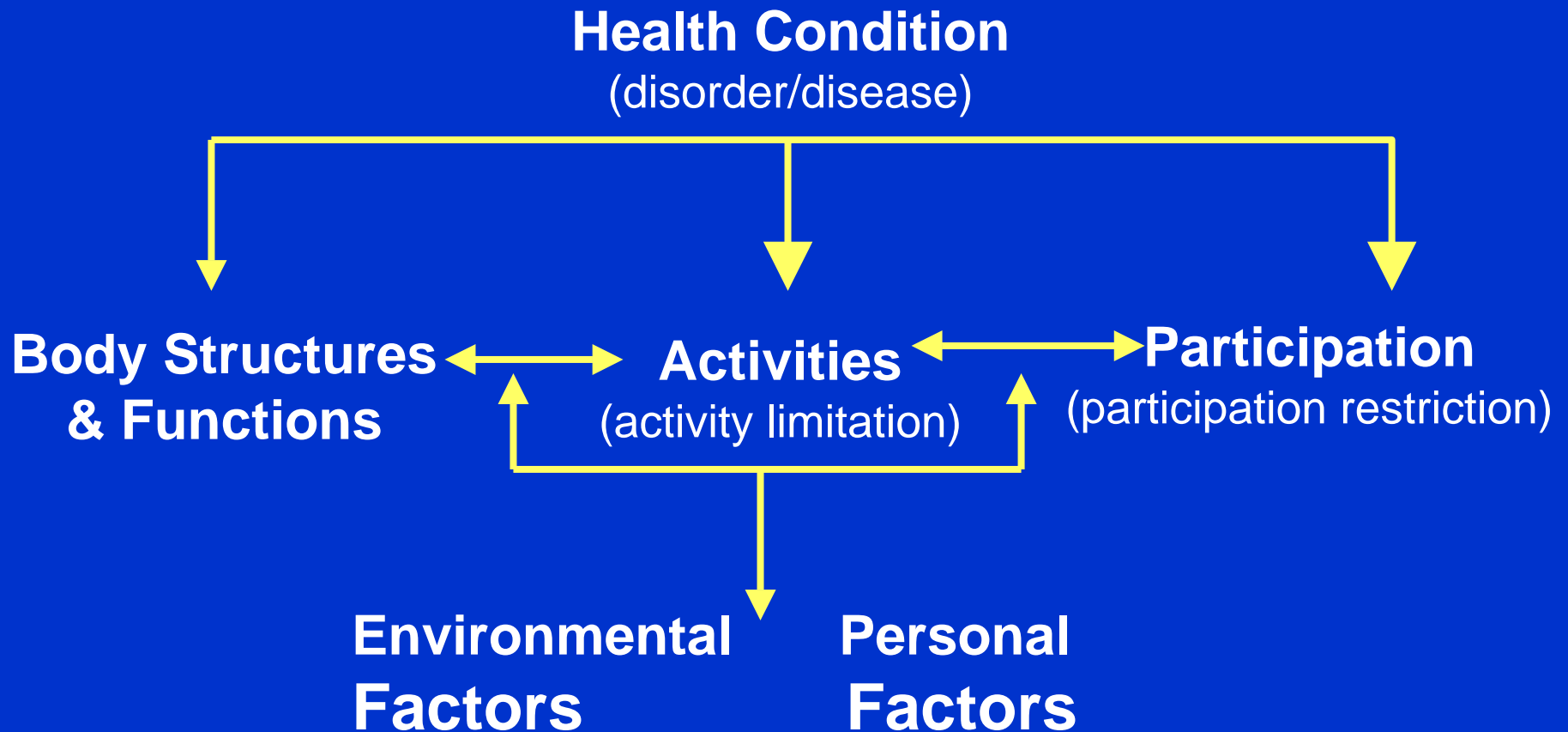
WHO family of classifications

- The ICD classifies diseases... ICF classifies health. Together, the two provide us with exceptionally broad and yet accurate tools to understand the health of a population and how the individual and his or her environment interact to hinder or promote a life lived to its full potential”. (Brundtland, 5/2002)

WORLD HEALTH ORGANIZATION FAMILY OF INTERNATIONAL CLASSIFICATIONS



ICF: Interaction of Concepts 2001



ICF Content

- Universe
 - *All* health related experiences
- Scope
 - “Description” of functioning & disablement
- Coverage
 - Inclusive, disablement as universal human experience
- Unit of classification
 - “attributes/experiences” of persons & “situations/circumstances” in which persons find themselves;
Persons are not the units of classification
- Organization
 - Body Structures & Functions, Activities, Participation are conceived as distinct but parallel dimensions

ICF (2001)

One Digit Level Classification

BODY FUNCTIONS

- Mental
- Sensory
- Voice, speech
- Cardiovascular, haematological, immunological & respiratory
- Digestive, metabolic, endocrine
- Genitourinary & reproductive
- Neuromusculoskeletal, & movement related functions
- Skin & related structures

BODY STRUCTURES

Nervous system
Eye, ear & related structures
Voice & speech structures
Cardiovascular, immunological & respiratory structures
Digestive, metabolism & endocrine
Genitourinary structures
Movement related structures
Skin & related structures

ICF (2001)

One Digit Level Classification

ACTIVITIES/PARTICIPATION

- Learning & applying knowledge
- General tasks and demands
- Communication
- Mobility
- Self-care
- Domestic life
- Interpersonal interactions and relationships
- Major life areas
- Community, social and civic life

ICF (2001)

One Digit Level Classification

ENVIRONMENTAL FACTORS

- Products & technology
- Natural environment
- Support & relationships
- Attitudes
- Services, systems & policies

• • • Rationale for version of ICF for children and youth

- Additional detail needed to document dimensions of health, disability, & environments unique to developmental period of childhood and youth
- Promote uniform concepts & terminology in health, education & related services nationally & internationally
- Systematize reasons of eligibility for habilitation/intervention services

Joint use of family of classifications to document dimensions of disability and health

<u>FOCUS</u>	<u>DIMENSION</u>
<ul style="list-style-type: none">• What is child's health status?	Health conditions-ICD
<ul style="list-style-type: none">• How does child's body/mind function?	Structure/Function-ICF
<ul style="list-style-type: none">• How does the child perform daily life activities?	Activities-ICF
<ul style="list-style-type: none">• How is child involved in roles/situations?	Participation-ICF
<ul style="list-style-type: none">• What are the things, conditions, & circumstances surrounding the child?	Environment-ICF

Documenting individual differences with the ICF

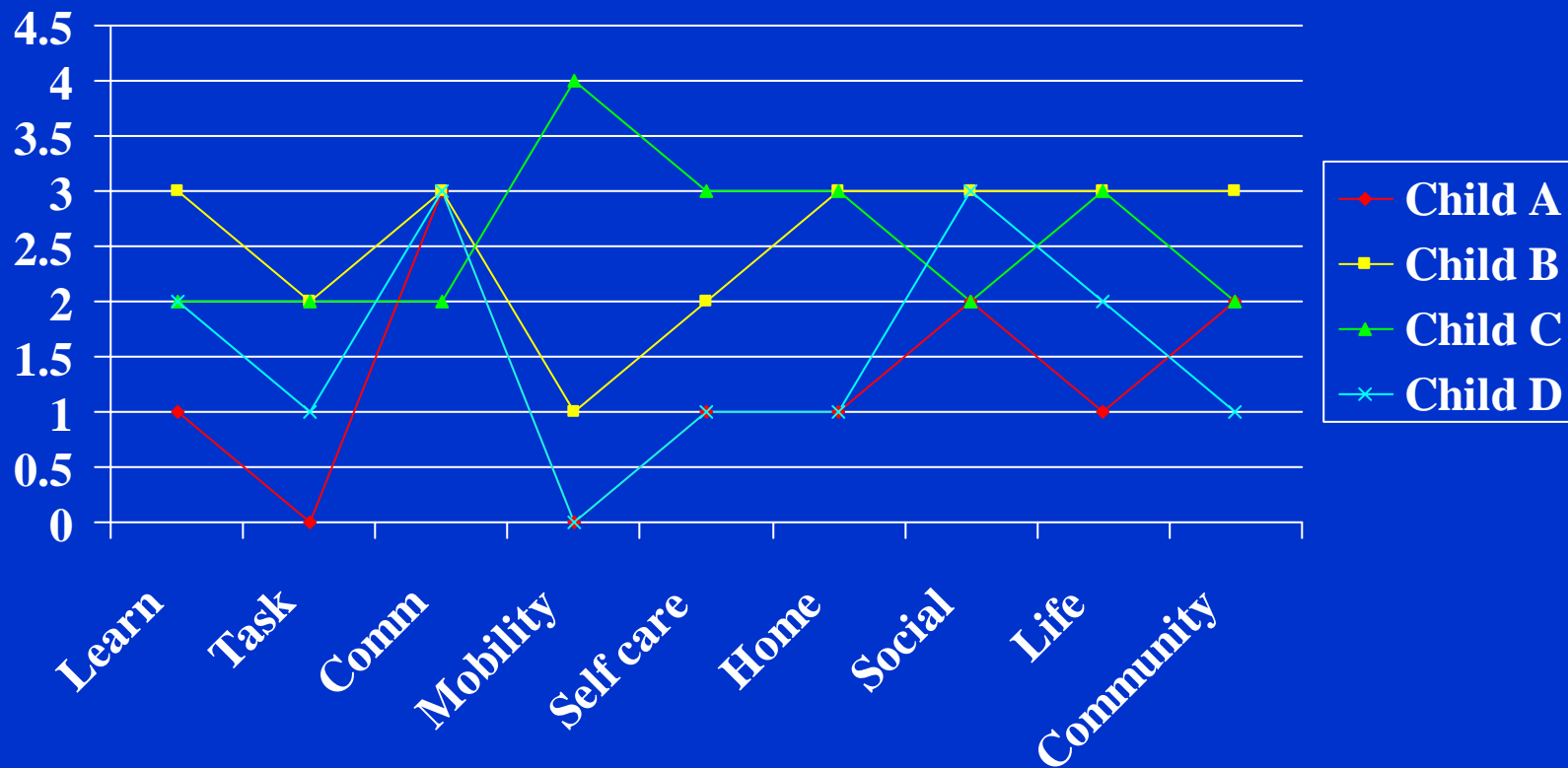
- Child A with disability

- b 1560 auditory perception
- b 2304 speech discrimination
- d 160 focusing attention
- d 166 reading
- d 820 school education

- Child B with disability

- b 144 memory function
- b 16810 expression of spoken language
- d 155 acquiring skills
- d 163 thinking
- d 330 speaking
- d 815 preschool education

- ICF: Individual profiles of children's functional limitations (Activity/Participation)



Development of a version of ICF for children and youth

- Work group developing adapted version for children and youth ready for publication in 2004
- Retain content of ICF applicable for children
 - Body function/Body structure
 - Activity/Participation
 - Environmental factors
- Add new content to encompass unique aspects of infancy, early/middle childhood, adolescence
- Identification and development of assessment instruments to complement children's version

• • Representative modifications: developmental considerations

- Developmental delay in manifestation of structure, function or activity performance (Aylward, 1997)
- Organization and regulation of behavior in infancy and early development (Prechtl, 2001)
- Motor coordination and laterality (Crawford, et al, 2001)
- Unique nature of habitual, frequent and occasional range of children's environment (Moore, 1990)
- Checklist development:
 - Profile individual differences (Southall et al., 2001)
 - Significance of precocious or delayed emergence of functions/structures as indicators

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• Development of the version of
ICF for children & youth :
structural aspects

- Build on guidelines in Appendix 8
- Identical conceptual framework of Body Function/Structure, Activities & Participation, Environment
- Identical hierarchical structure of chapters, blocks and categories



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Development of the ICF version for children and youth:

- Descriptions modified or expanded
- New content assigned to unused codes
- Inclusion/exclusion criteria modified and/or expanded
- Qualifier modified to encompass extent or magnitude of problem of developmental nature

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- **New content assigned to unused codes**

- **d 120 Other purposeful sensing**

- Using the body's other basic senses intentionally to experience stimuli, such as touching and feeling textures, tasting sweets or smelling flowers.

- *d 1200 Mouthing*
- *d.1201 Touching*
- *d.1202 Smelling*
- *d 1203 Tasting*



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New content assigned to unused codes: Body structures

- s 115 Structure of white matter
 - *s 1150 Corpus callosum*
- s 7100 Bones of the cranium
 - s 71000 Sutures
 - s 71001 Fontanelle

• New content assigned to unused codes: Body Structures

- s 320 Structure of mouth
 - s3200 Teeth
 - *s32000 primary dentition*
 - *s32001 permanent dentition*
 - s 3201 Gums
 - s 3202 Structure of palate
 - s 32020 Hard palate
 - s 32021 Soft palate
 - s3203 Tongue
 - s 3204 Structure of lips
 - s 32040 Upper lip
 - s 32041 Lower lip
 - s 3205 Phylum
 - *s 3205 Phylum*
 - *s 3206 Philtrum*

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- Modification of qualifier to encompass problem of developmental nature

- Generic qualifier for Body Functions and Body Structures, used to indicate the extent or magnitude of *a problem, deviation or delay*, :
 - *0-No problem*
 - *1-Mild problem*
 - *2-Moderate problem*
 - *3-Severe Problem*
 - *4-Complete problem*

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• **New content assigned to unused codes: Body functions**

- *b 1566 Haptic perception- Mental functions involved in distinguishing shapes and forms including reading Braille*
- *b 1567 Proprioception- Mental functions involved in awareness of limb positions and body boundaries*

Example of adding codes

- Chapter 8- Major Life Areas
- Play (d805-d809)
- d805 Playing- engaging in spontaneous or organized activities with objects/toys or others
 - d8050 solitary play
 - d8051 functional play
 - d8052 symbolic/pretend play
 - d8053 social play

Field trials

- Content validation:
- Review of content by consumers, providers, policy makers, researchers at an international level
- Clinical utility:
- Application of the taxonomy in clinical settings with children and youth with disabilities covering a wide range of age, conditions and severity levels

Contributions of the ICF: : individual level

- Tracking developmental manifestations of disability
- Linking classification to other measures of development and behavior
- Provide basis for documenting individual differences of children with disabilities
- Document health conditions and their consequences

Contributions of the ICF: group/system level

- Use in censuses and population based surveys
- Development of core-sets for documenting specific aspect/facet of childhood disability
- Use of common indicators for eligibility across agencies and systems
- Monitoring of policies and initiatives for child health and development

Contributions of the ICF: potential applications

- conceptual framework for defining content
- item selection consistent with ICF codes
- assigning ICF codes to survey data
- cross-walk ICF codes common across different measures

(ICF, WHO, 2001)

<http://www.who.int/icf/icftemplate.cfm>



Gracias Thanks

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