Republic of Namibia

EARLY IDENTIFICATION AND INTERVENTION SERVICES FOR YOUNG CHILDREN WITH DEVELOPMENTAL DELAYS AND DISABILITIES IN NAMIBIA

# Introduction to the International Classification of Functioning, Disability and Health: Children & Youth version (ICF-CY)

4

UNITED NATIONS NAMIBIA

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# MANUAL 4:

# Introduction to the International Classification of Functioning, Disability and Health: Children & Youth Version (ICF-CY)

Republic of Namibia

Namibia Statistics Agency

UNPRPD MPTF
Partnership on the Rights of Persons with Disabilities

# CONTENTS

FIGURES AND TABLES | **2**
ACKNOWLEDGEMENTS | **3**
FOREWORD | **5**
PREFACE | **6**
ABBREVIATIONS AND ACRONYMS | **7**
GLOSSARY OF ICF AND RELATED TERMINOLOGY | **8**
1. INTRODUCTION | **11**
2. THE ICF TAXONOMY | **14**
    2.1 Orientation to health | **14**
    2.2 Biopsychosocial model | **14**
    2.3 ICF Components | **17**
    2.4 ICF Framework | **21**
    2.5 Intervention | **22**
3. THE ICF-CY SYSTEM | **23**
    3.1 Description | **23**
    3.2 Rationale | **23**
    3.3 Revision of the ICF | **24**
    3.4 Usefulness | **27**
4. APPLICATION | **30**
    4.1 Presence of health condition | **30**
    4.2 Key construct: Participation in life | **32**
    4.3 Preparation and planning | **34**
    4.4 Classification procedure | **37**
    4.5 Coding system | **39**
    4.6 Core and code sets | **49**
5. CASE STUDIES | **53**
REFERENCES | **64**
END NOTES | **67**
APPENDIX 1: CHILD FUNCTIONING MODULE (CFM) (UNICEF / WASHINGTON GROUP OF DISABILITY STATISTICS 2016) | **68**
APPENDIX 2: MOST ADDITIONS TO THE ACTIVITIES AND PARTICIPATION (d) CHAPTERS OF THE ICF-CY |**73**
APPENDIX 3: ICF ETHICAL GUIDELINES | **77**
APPENDIX 4: BODY FUNCTIONS (b CHAPTERS) | **78**
APPENDIX 5: BODY STRUCTURES (s CHAPTERS) | **79**
APPENDIX 6: ACTIVITIES AND PARTICIPATION (d CHAPTERS) | **80**
APPENDIX 7: ENVIRONMENTAL FACTORS (e CHAPTERS) | **81**
APPENDIX 8: STATISTICAL NORMAL DISTRIBUTION | **82**
APPENDIX 9: DISTRIBUTION OF EVERYDAY LIFE SITUATIONS (ELS) | **83**
APPENDIX 10: ICF-CY DEVELOPMENTAL CODE SETS | **84**

# FIGURES AND TABLES

Figure 1: Stakeholders associated with developmental delays and disabilities
Figure 2: The ICF model
Figure 3: Interaction of the ICF components
Figure 4: The ICF Structure
Figure 5: Expanding life experiences of the developing child
Figure 6: The EDD code set

Table 1: Examples of components of functioning linked to health conditions
Table 2: The ICF-CY classification procedure in 3 steps
Table 3: The qualifiers for Body structures
Table 4: Qualifiers for extent of impairment or developmental delay
Table 5: Qualifier scale guideline for Activities and Participation indicators
Table 6: Environmental factor qualifiers
Table 7: Coding functional aspects described in sources of information

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The project is jointly being implemented by UNDP, UNFPA and UNICEF and supported by the United Nations Partnership on the Rights of Persons with Disabilities (UNPRPD), under the coordination of the Office of the President: Disability Affairs. The United Nations Partnership on the Rights of Persons with Disabilities Multi-Partner Trust Fund (UNPRPD MPTF) is a unique collaboration that brings together UN entities, governments, organizations of persons with disabilities (OPDs), and broader civil society to advance the rights of the Convention on the Rights of Persons with Disabilities (CRPD) and disability inclusive Sustainable Development Goals (SDGs). We thankfully acknowledge the financial contribution of the UNPRPD in supporting Namibia to implement the project which is aimed at strengthening the voices of persons with disabilities.

These manuals were produced by Dr Hetta van Niekerk, Educational Psychologist under the supervision of the UNICEF Namibia Country Office. Inputs were received from individuals, parents, representatives of organizations of persons with disabilities and disability service providers, non-governmental organizations and institutions of higher learning. In addition, the Ministries of Health and Social Services; Education, Arts and Culture, Gender Equality, Poverty Eradication and Social Welfare, Office of the President: Disability Affairs; as well as health experts from both the private and public sectors also contributed.

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The findings, interpretations and conclusions expressed in this document are those of the author and do not necessarily reflect the policies or views of UNICEF or the United Nations.

It is hoped that these manuals will contribute to further enhancing the capacities of individuals, parents and institutions in the early identification, assessment and referral to services of children with disabilities before formal education.

Editing, layout and design by Jo Rogge.

**Sen Pang**
UN Resident Coordinator in Namibia

# FOREWORD

> The essence of our effort is to see that every child has a chance. We must assure each an equal opportunity not to become equal, but to become different – to realize whatever unique potential of body, mind and spirit he or she possesses.
>
> • John Martin Fischer

Namibia has committed to attaining the Sustainable Development Goals (SDGs) by the year 2030. Early childhood development is key to Goal 4 of the SDGs:

*"Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all."* Similarly, target 4.2 states: *"By 2030 ensure that all girls and boys have access to quality early childhood development, care and pre-primary education so that they are ready for primary education."*

During October 2019, the United Nations Children's Fund (UNICEF) Namibia facilitated an analysis of the scope and quality of currently available global good practice on the early identification and early intervention (IEIE) services for young children with disabilities and developmental delays in Namibia. It also identified the need to a develop a training manual for different service providers. This manual will focus on providing both service providers and parents with practical information on how to identify children with disabilities as early as possible and where to refer them for early assessment and early intervention.

During January-February 2020, extensive focus group discussions were held with a range of stakeholders involved in service provision to children with developmental delays and disabilities in Namibia. Barriers, gaps, as well as strengths, in terms of current service delivery, were identified. Data was also collected by means of an electronic questionnaire from educational institutions, disability organisations and health professionals. The contents of this manual are consistent with broad themes that emerged from consultations with over 200 stakeholders from all 14 regions of Namibia.

Service delivery is organised to be child-centred and family-focused, and if applicable, multidisciplinary in nature. The empowerment of parents and guardians of young children with developmental delays and disabilities, is most important.


**Ester Anna Nghipondoka**
Minister of Education, Arts and Culture

# PREFACE

Early childhood spans the developmental period from conception to eight years of age. The child's first 1000 days - from conception to two years of age - are the most critical in child development as a child's brain develops rapidly during this stage and neural connections are formed.

When a child's brain fails to get what it expects and needs, especially during the most sensitive and rapid periods of development early in life, the amount of effort required to set it back on track later in life is enormous and optimal outcomes are far less likely.

The early years of a child's life provide an important window of opportunity to prepare a solid foundation for health, social well-being, lifelong learning and participation, and to prevent potential delays in development and disabilities. Early identification of disabilities in children is crucial to ensure future access to the appropriate intervention and support needed, to reach their full potential. Appropriate early intervention can remove or reduce the risk of secondary issues related to ongoing developmental difficulties.

Consistent with the UN Convention on the Rights of Persons with Disabilities (UNCRPD), disability is conceptualised as an interaction between the person's impairment and a variety of barriers that may prevent the individual's full enjoyment of life situations to the same extent as others. Moreover, from a human rights perspective, all children – with or without developmental delays and disabilities – should have similar opportunities with a view to optimally developing their potential.

This manual is intended to guide all stakeholders involved with children with developmental delays and disabilities in early childhood. It focuses on the improvement of service delivery in early identification of varied development and disabilities, as well as effective intervention. The manual further provides information for parents and/or guardians about their children's developmental issues, and guidance and support in caring for them.

The Parent and Guardian Manual contains practical and useful information for training purposes. This manual can be used as resource together with additional materials for existing workshops and courses with these caregivers.  Manuals 1 to 4 are intended for study and research purposes for all involved with young children with disabilities.

Responsive caregiving of young children with developmental delays or disabilities is approached from an IECD perspective in which the healthcare system, ECD programmes and parents and/or guardians collaborate with one another. Information selected from the theoretical manuals (1 – 4), is concisely presented, practically applied and graphically supported. It is important to point out that stigma and discrimination against children with disabilities and labelling them must be avoided at all costs. Working with young children with disabilities requires a carefully personalised approach. The importance of meaningful parental involvement in their children's early years and ensuring access to early childhood development services for the child with a disability are emphasised.

**Alexia Manombe-Ncube**
Deputy Minister for Disability Affairs

# ACRONYMS & ABBREVIATIONS

| | |
|---|---|
| AAC | Alternative and Augmentative Communication |
| ADL | Activities of Daily Living |
| CCN | Complex Communication Needs |
| EDD | Early Delay and Disability |
| ESL | Everyday Life Situations |
| ICD-10 | International Statistical Classification of Diseases and Related Health Problems, 10th version |
| ICF | International Classification of Functioning, Disability and Health |
| ICF-CY | International Classification of Functioning, Disability and Health: Children and Youth Version |
| SD | Standard Deviation |
| UN | United Nations |
| UNCRPD | UN Convention on the Rights of Persons with Disabilities |
| UNESCO | United Nations Educational, Scientific and Cultural Organisation |
| UNICEF | United Nations Children's Fund |
| WG | Washington Group |
| WGSD | Washington Group of Disability Statistics |
| WHO | World Health Organisation |

# GLOSSARY OF ICF AND RELATED TERMINOLOGY

**Activity**
a person's execution of a task or action

**Activity limitation**
a person's difficulty to execute a task or action

**Aetiology**
the cause or set of causes of a disease or condition

**Assistive technology**
any product, instrument, equipment or technology adapted or specially designed for improving the functioning of a person with a disability

**Bioecological theory**
Theory of human development in which a child's development unfolds through progressively complex, relatively stable and continuous reciprocal interactions in different systems

**Barriers**
are aspects in the environment that limit a person's functioning as a result of either their absence or presence

**Body functions**
physiological functions of the body systems, including psychological functions

**Body structures**
anatomical parts of the body, e.g. organs, limbs and their components

**Capacity**
what a person with a health condition can do in a standard environment

**Code set**
a checklist of categories that addresses specific concerns of functioning that was developed systematically by its users

**Core set**

a checklist of standard categories developed by means of a scientific procedure to represent the classic functioning profile of a person with a specific health condition or in a particular setting

**Developmental delay**

a significant lag in terms of one or more expected developmental milestone or the emergence of functions, structures or capacities

**Disability**

an umbrella term for impairments, activity limitations and participation restrictions

**Environmental factors**

the physical, social and attitudinal context in which people live their lives

**Everyday life situation**

a sequence of actions that constitute a functional activity for engaging meaningfully / purposefully in a natural environment

**Functioning**

an umbrella term that includes all body functions, activities and participation domains

**Granularity**

level of categorical detail provided

**Habilitation**

the practice of assisting children with developmental delays or disabilities to strengthen abilities, and to gain skills and knowledge

**ICD-10 code**

diagnostic code according to the International Statistical Classification of Diseases and Related Health Problems, 10th version. It is widely required for medical health insurance

**Impairment**

problem in body function or structure such as significant deviation or loss

**Participation restriction**
health problems that can hinder people's involvement in different life events

**Performance**
what a person with a health condition can do in her / his typical environment

**Qualifier**
a number to record the presence and severity of a problem in functioning on the physical, personal and social levels

**Rehabilitation**
the process during which a person is assisted to regain abilities, skills and/or knowledge that was lost or compromised as a result of a change in functioning

**Social support network**
the group of adults involved in the life of a child with a disability at any point in time, by taking roles in terms of caregiving, support, education and decision making - parents, teachers and assistants, and members of a multidisciplinary team and other health professionals

**Universal design**
the orientation towards the planning and composition of every environment in order for it to be accessed and utilised by everyone regardless of age, disability or group size

# 1 INTRODUCTION

The target group for this introductory training manual on the International Classification of Functioning, Disability and Health (ICF), and in particular the Children and Youth Version (ICF-CY), is professional stakeholders in the multidisciplinary field of early identification and intervention of developmental delays and disabilities.

**Figure 1: Stakeholders associated with developmental delays and disabilities**


The ICF is WHO's framework for health and disability. It is the only classification system that is universally recognised and intervention strategies can be designed based on this knowledge. The ICF offers: **"a framework for the description of human functioning and disability and for the documentation, organisation and analysis of this information."** (WHO 2013: 18)

The ICF is a multipurpose classification intended for a wide range of uses in different sectors. It is also the conceptual basis for the definition, measurement and policy formulations for health and disability. This model is useful on the level of therapeutic practice as well as in health and education management.

Implementing the ICF as a screening tool for functional problems will enhance provision of therapeutic services associated with developmental variations, whether in private practice or in the public sector. Parent and/or caregiver involvement (their participation in family life) is advisable when intervention strategies are planned.

The advantages of including the use of the ICF in the training of healthcare professionals are three-fold:

- It is a valuable learning tool to develop skill in clinical reasoning.
- It provides a platform for inter-professional collaboration as well as multidisciplinary team work, using a holistic and person-centred approach.
- Its application is wholly suited to the field of public health, because of its emphasis on contextual factors.

The ICF framework is complimentary to the theory of inclusive education. In fact, the notion of participation is fundamental to understanding this model and its use.

In order to be relevant for education, information on problems, deficits or impairments should be understood in the context of participation in education. It is important to note that relationships between impairment and academic achievement or between capacity and performance, in a given educational environment are never straight forward, but need to be explored and understood. In the context of education, functional information on impairments should be combined with information about functioning relevant for learning and understood in the context of the specific requirements for successful participation that may differ considerably from one educational setting to another.

Individualised profiles of functioning inform strategies for inclusion, in order to facilitate the optimal development of the learning potential of all children.

Introducing the ICF framework in this training manual is intended to bring about a shift in understanding of the construct 'disability' and reinforce a paradigm in which disability is approached from a multifocal and dynamic perspective.

Stakeholders trained on the ICF model work as agents of change in communities. Since the intention is to empower professionals working with children in the developmental phases of infancy and early childhood, case studies specific to these age groups have been included for further clarification of theory and practice exercises.

To enhance comprehension of the contents, a glossary of ICF and related terminology is provided at the end of the training manual.

**It is suggested that the manual is used in conjunction with the following manuals:**

| | |
|---|---|
| Manual 1 | Understanding child disability rights |
| Manual 2 | Early childhood development |
| Manual 3 | Understanding developmental delays and disabilities |

The full version of the ICF-CY manual can be downloaded at:
https://apps.who.int/iris/handle/10665/43737

# 2 THE ICF TAXONOMY

## 2.1 Orientation to health

Disability is viewed as the interaction between impairment and socially constructed barriers that hinder the person with functional limitations to enjoy as meaningful a life as her/his peers do.

> Persons with disabilities are: "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."
> The UN Convention on the Rights of Persons with Disabilities (UNCRPD)

The development of the International Classification of Functioning, Disability and Health (ICF) was motivated by the intention to establish a multi-purpose classification system of health and health-related domains and to provide a common language to the variety of sectors involved in the field of health and disability. By describing the health-disability continuum, stigma is reduced.

The 191 Member States of the WHO have adopted the ICF as the basis for the scientific standardization of data on health and disability worldwide.

ICF puts the notions of 'health' and 'disability' in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some disability. This is not something that happens to only a minority of humanity. ICF thus 'mainstreams' the experience of disability and recognises it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability.

## 2.2 Biopsychosocial model

The ICF is described as a **biopsychosocial model**, ie., a combination of two conceptual models of disability. (Figure 2)

According to the **medical model**, disability is intrinsic to a person due to disease, disorder or trauma. Medical treatments or other forms of professional intervention are deemed necessary to rectify the 'problem' on the basis of a 'diagnosis.'

The **social model** on the other hand proposes that the problem of disability is created by society through an unaccommodating physical environment brought about by attitudes and other features of the social environment..

CASE STUDY 5

## Ridhima's story

Issues with the medical model of assessment

Ridhima was in Grade 5 when her class teacher and school psychologist asked her mother to get her assessed for learning disability. She was failing in exams and the teachers complained that she either day dreamed in the class or kept talking to her friends. In Grade 6, her assessment for learning disability began at the municipal hospital designated for assessments in Mumbai.

After a series of assessments, she was diagnosed as having ADHD. The psychologist's advice was to put her on medication and referred her back to the doctor. The doctors reviewed her case and prescribed medication for a month without consultation with the parents. On asking what the medicine is, the response given was, 'it is allopathy medicine.'

Except for the initial interview with the parents to learn about the child's behaviour, throughout the process there was no discussion with or counselling of the parents. The assessment was completely one-sided with doctors neither explaining the diagnosis nor seeking consent from parents before prescribing medical treatment. No school-based intervention for improvement in learning was planned, neither the notes, observations and results of the assessment were shared with the parents or the school. Only the disability certificate was handed over for submission to the school.

After getting the certificate, the school told the parents not to worry as Ridhima will be promoted to the next class until grade 8. In grade 9, her disability certificate will be useful, as it will allow her to choose subjects she finds easy and she will get exemptions in board exams.

**Source**: Bhagyalaxmi Velugu, based on observations of Ridhima's assessment schedules (entire process) at the hospital and interview with the parents.

**Power dynamics** determine the relationship between an expert and a novice in the medical model. The patient is dependent on the service provider as the authority and the primary source of knowledge. In the social model, **the parent and the child are seen as the authority,** rather than the professional. This approach recognises multiple sources of knowledge to address the functional issues related to impairment. Gaining access to these resources creates a dynamic collaboration among the family system and one or more service provider. This facilitates the client's empowerment.

**Figure 2: The ICF model**

On their own, neither model is adequate, although both are partially valid. Disability is a complex phenomena [sic] that is both a problem at the level of a person's body, and a complex and primarily social phenomena [sic]. Disability is always an interaction between features of the person and features of the overall context in which the person lives, but some aspects of disability are almost entirely internal to the person, while another aspect is almost entirely external. In other words, both medical and social responses are appropriate to the problems associated with disability; we cannot wholly reject either kind of intervention.

**The ICF is a tool for measuring functioning in society** with its focus on health and health-related outcomes. Health is considered as not only the absence of disease, but also wellbeing in all aspects of life. Working with the two systems in tandem is understood to be an understanding of health and how the interaction between the individual and the environment hinders or facilitates a good life.

A holistic approach to the management of certain health conditions, calls for the careful consideration of medical diagnoses (in accordance with the **International Statistical Classification of Diseases and Related Health Problems, 10th version (ICD-10)** codes) in conjunction with the ICF framework. Individualised and personal profiles of functioning can subsequently be improved through modifications to the environment. When intervention is approached in this way, the incidence and severity of disabilities within populations are challenged.

**The ICF is a useful tool for all persons with disabilities, for two reasons:**

- **Health care and rehabilitative needs can be identified; and**
- **The impact of physical and social contexts on life experiences can both be**
- **identified and factored in.**

**The Washington Group (WG) questions were designed to improve global disability data.**

They are targeted questions on individual functioning intended to provide a quick and low-cost way to collect data, which allows disaggregation by disability status.

The questions are largely based on a persons' perceived functioning within their real lived experience and therefore in accordance with the rationale of the ICF.

### The Washington Group Questions

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, (for example understanding or being understood by others)?

Each question has four response categories:

1. No, no difficulty,
2. Yes, some difficulty,
3. Yes, a lot of difficulty and
4. Cannot do it at all.

## 2.3 ICF Components

**The conceptual categories of the ICF system are described below. (Figure 3)**

- A **health condition** indicates acute or chronic disease, disorder, injury or trauma. Congenital anomaly and genetic predisposition also fall under this collective term.

- **Functioning** comprises the harmonious interaction of body structures and functions (including the brain), and activities and participation.

  - ➦ Body structures refers to the anatomical parts, and body functions for the physiological and psychological functioning of an individual.

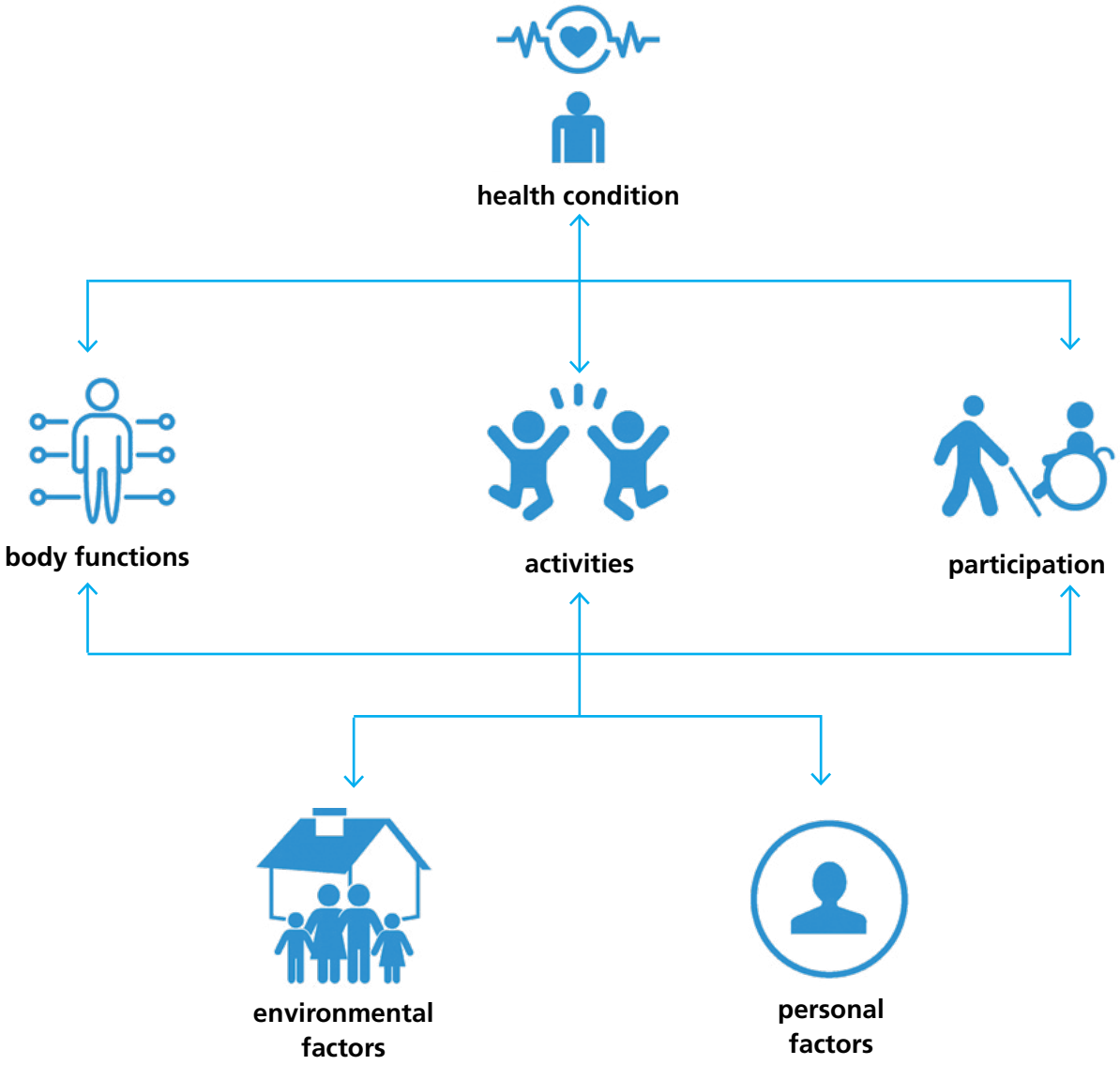
  - ➦ Activities refers to the execution of actions and tasks.

  - ➦ Participation denotes the person's involvement in life situations.

  - ➦ Elements in the individual's environment are facilitators, when they improve functioning due to either their absence or presence.

- **Contextual factors** are the circumstances in which a person lives.
  - ➦ Environmental factors consists of all aspects of the external world in which the individual functions.
  - ➦ Personal factors refers to all descriptive features of the individual - age, gender, social status, habits and educational level.

**Figure 3: Interaction of the ICF components**



The complexity of the relationship between functioning and contextual factors i.e. environmental and personal, differs.

**The following distinction is therefore made:**

**Performance** describes the actual activities of an individual in the context in which she or he lives presently. It is considered to be a descriptor of the lived experience.

**Capacity** refers to the individual's ability to perform a task or action. A standardised environment is used to assess the person's highest probable level of functioning or full capability.

Having access to both performance and capacity data enables the ICF user to determine the 'gap' between capacity and performance. If capacity is less than performance, then the person's current environment has enabled him or her to perform better than what data about capacity would predict - the environment has facilitated performance. On the other hand, if capacity is greater than performance, then some aspect of the environment is a barrier to performance.

A dynamic process is set in motion through the interplay of the different ICF components. Therefore, as is characteristic of functional systems, intervention that targets one component may also have an effect on related components.

## Interaction between health condition and environmental factors

According to the interactionist perspective, disability is created by an interaction of factors, which makes measurement particularly difficult: a characteristic of a child which might not lead to disability in one context might limit their participation in education in another. For example, a child who cannot see the chalkboard clearly without glasses could be considered to have a disability of educational significance if glasses are not available and the chalkboard is in poor condition.

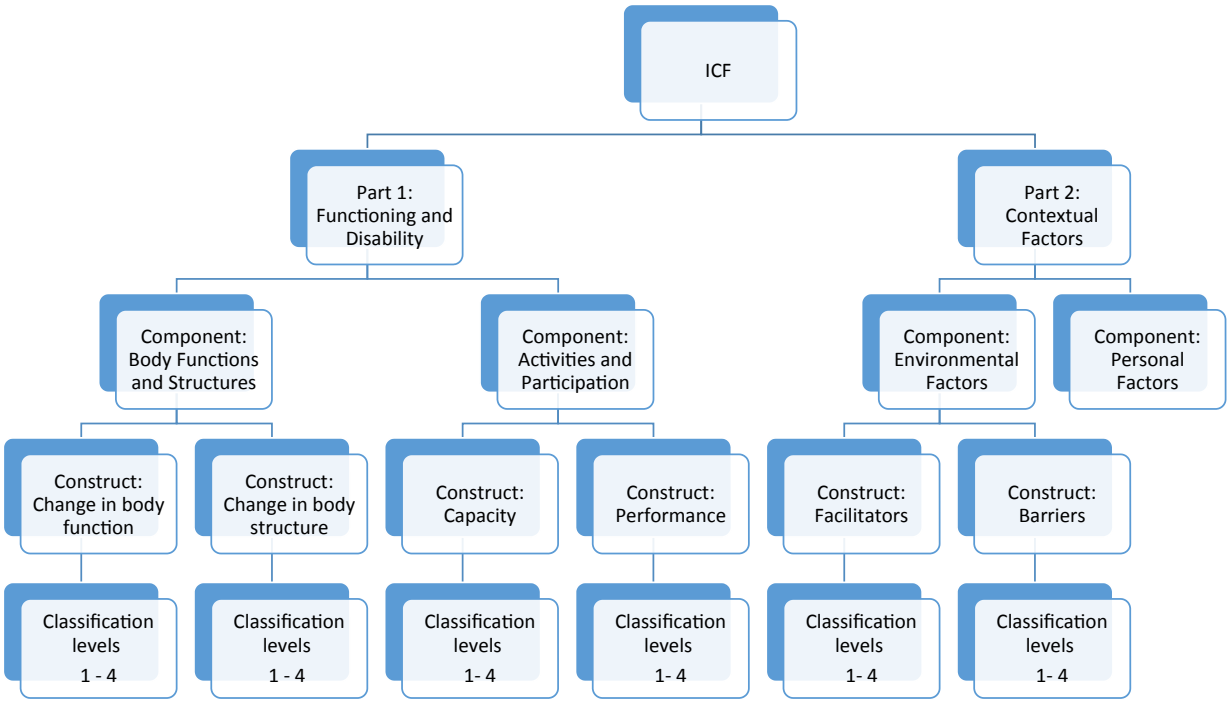
Studies of disability have measured different elements of the interaction, collecting information on impairment (e.g. visual impairment), activities/activity limitations/functioning (e.g. seeing the chalkboard) and participation (e.g. attending and learning in school alongside peers), as well as barriers and enablers that help create or dismantle disability (e.g. poor quality chalkboard, few textbooks and bullying as barriers, and attentive teachers addressing bullying and provision of vision aids as enablers).

**(Education Development Trust & UNICEF 2016: 33) [emphasis added]**

## 2.4 ICF Framework

The hierarchical structure of the ICF is key to organising the information gained from analysing the interactions of its different constructs according to a biopsychosocial model. (Figure 4)

**Figure 4: The ICF Structure**




The structure is operationalised by the systematic allocation of codes. An alphanumerical system is employed to indicate the nature and extent of functioning or disability. Granularity refers to the level of categorical detail provided.

The higher the number of digits in a code, the more specific its description. The digits of a number from left to right represent a continuum from general to specific. The level of descriptive coding is optional, but the use of qualifiers to indicate the extent of impairment, limitation or restriction, and the impact of environmental factors is compulsory.

Although personal factors are considered to be part of the context that plays a role in an individual's functioning, these aspects are excluded from the classification system. It is recommended that users of the system integrate these aspects in an individual's profile of functioning.

The impetus of the ICF conceptual framework is that everyone is included in the experiences of daily life. With the emphasis on participation or involvement in life, the gap between capacity and performance is of special interest. Every person is supposed to live in circumstances in which their functioning is in general accordance with their potential.

> The model of health becomes a model of disability when a severity qualifier is applied to indicate impaired functioning, i.e. the extent of impairments, activity limitations, or participation restrictions. (Adolfsson 2011: 18)

## 2.5 Intervention

**There are three levels of intervention associated with the ICF components. Prevention is also considered as a form of intervention:**

**Primary prevention means that the disability is prevented from occurring. Concerted efforts are made to reduce its incidence, eg. immunization programmes.**

**Secondary prevention reduces the duration or severity of the disability. Early identification through screening followed by strategies of intervention curbs the impact of disability.**

**Tertiary prevention is for managing the impact of existing disability, eg. habilitation and rehabilitation programmes.**

# 3 THE ICF-CY SYSTEM

## 3.1 Description

The **International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)** is an extension of the ICF classification system. Additions to categories and modifications have been made to accommodate the age range from birth to 18 years. (see Appendix 2)

The ICF-CY offers a conceptual framework and a common language and terminology for recording problems manifested in infancy, childhood and adolescence involving functions and structures of the body, activity limitations and participation restrictions, and environmental factors important for children and youth. With its emphasis on functioning, the ICF-CY can be used across disciplines, government sectors and national boundaries to define and document the health, functioning and development of children and youth.

## 3.2 Rationale

**The rationale for developing the ICF-CY was twofold:**

- From a philosophical point of view, children's rights are fundamental. The UNCRPD promotes a rights-based approach to preventing disability during childhood. The course of childhood development therefore had to be incorporated in the classification of functioning.

- The need for a comprehensive system for children was recognised. Children are developing individuals and they differ from adults in the presentation of health conditions, functioning and disability. The ICF-CY validates children's rights in terms of health care, education, and social and habilitation services.

In contrast to the task of documenting functioning in adults, documenting child characteristics can be more challenging in that the developing child is a 'moving target,' manifesting rapid changes in physical, social and psychological functioning during the first 2 decades of life.

## 3.3 Revision of the ICF

The original ICF system was revised between 2002 and 2005 to make it more compatible with the characteristics of child and adolescent development.

**The following four conceptual notions were specifically considered:**

### 1. The child develops within the context of the family

**Dependency is a function of immaturity.** The child moves progressively from dependency on others for all activities in infancy towards physical, social and psychological maturity and independence in adolescence. The child relies on constant interactions with attachment figures in a social environment established and maintained by family. The family system is thus vital in relation to the child's functioning in life situations. It is within the child's unique relational system that she or he acquires a myriad of skills over the developmental span.

The younger the child, the more likely that opportunities to participate are defined by parents, caregivers or service providers. The role of the family environment and others in the immediate environment is integral to understanding participation, especially in early childhood.

For the very young child, the family constitutes her/his social environment. Even though their social context gradually also expands to include peers and other significant figures, family continues to be significant in a child's life.

### 2. Developmental delays

**Developmental delays signal an increased risk of disabilities.** A developmental delay is described as an age-specific gap in the emergence of functions, structures or capacities related to the different domains of development. Physical and psychological factors may play a role. Not all developmental delays are permanent and the severity of the impairment may change over time.

### 3. Participation in life situations

**Participation** implies an interaction between individual and environment, and is therefore linked to life situations. Despite having a similar need for activities and participation as

any other child, the opportunities for a child with a disability to enjoy life experiences are often compromised in some way or another. Mastery of certain tasks can be difficult and this complicates involvement in a life situation. Also, children with severe, multiple and/or complex impairments require assistance to execute daily activities. Much time can be spent in the company of adult caregivers who not only give support, but also facilitate their participation in life situations. Promoting the development of autonomy should be a key focus area.

**Typical early childhood development is associated with at least three of the activities and participation domains:**

- social interaction,
- play and exploration, and
- mobility, whether other-directed or self-directed.

## The child within the family

Much of the lived experience of children is acquired in a family context such as leisure and shopping activities, visiting relatives and going on holiday. Thus the family is an important environmental factor interacting with the child; and conversely the child inevitably impacts on the participation of the other family members. The difficulty in unravelling this interaction can be overcome by recognising that for some aspects and stages of childhood, participation is better assessed as it applies to the family. Another example of the blurring of parental and child participation is evident when we consider economic and social domains.

Many families with a child with disability are impoverished by uncompensated extra costs and restricted employment opportunities. This is exemplified by a comparison of community activity patterns between 2 to 5-year-old children with and those without disabilities. Though the study showed that the participation of children with and without disabilities was generally similar, most of the lower frequencies for the participation of children with disabilities were in family-oriented activities which depended on 'discretionary financial resources'.

Therefore, where families of children with disabilities participate less, this may reflect indirect effects upon a family's financial resources rather than a direct impact of the child's impairment(s). In summary, it may not be practical to place a clear boundary around the child when describing their participation; survey instruments should encompass the notion that for some purposes the child participates as part of a family rather than as an individual. (McConachie et al 2006: 1158)

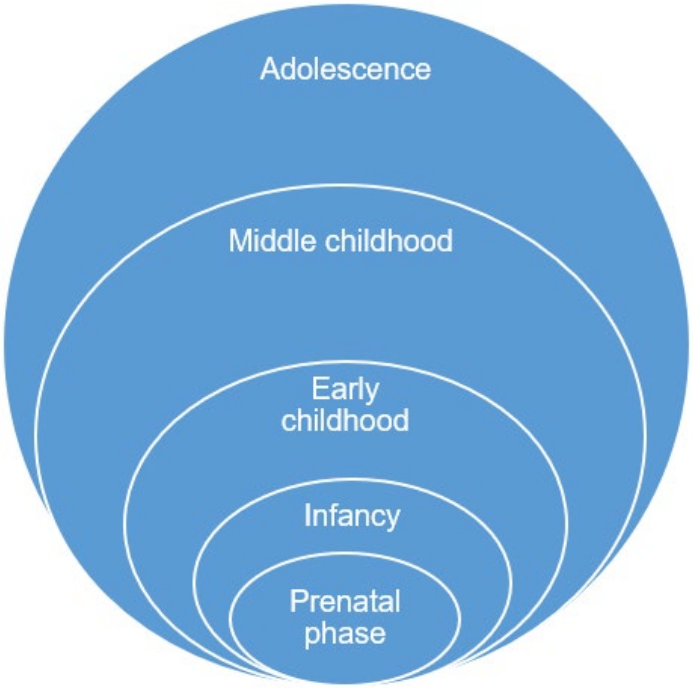
Children's participation in life situations is organised according to expected milestones on a developmental track. Attachment relationships unfold in different phases, and so do relationships with peers. Play and learning are the two other facets that are characterised by developmental markers.

## 4. The physical, social and attitudinal environment of the child

Consistent with the bioecological theory of human development, the biopsychosocial model of disability recognises the significance of the environment in achild's life. However, the nature and complexity of the child's environmental contexts vary in accordance with the developmental course from infancy to adolescence. The two most prominent variables are dependence and competence.

When one considers the impact of physical and social elements of the environment on the functioning of the child, disability during childhood can sometimes be prevented by way of environmental support. The younger the child, the more dependent she or he is on caregivers in fulfilling her/his developmental needs. Adjustments can be facilitated in the immediate environment of the child regarding basic health and well-being, assistive devices (where applicable), support and education for parents and/or caregivers, or distally in terms of legislation and national policies on health care, education and social services. (Figure 5)

**Figure 5: Expanding life experiences of the developing child**




## 3.4 Usefulness

Since its development, the benefit of employing the ICF-CY has been widely publicised. Stakeholders have an established universal non-stigmatizing and strength-based language at their disposal The comprehensiveness of the system not only reflects the multidimensional nature of health conditions, it also allows for the various disciplines in the field of disability to each concentrate on different components . When professionals are knowledgeable about the classification system, they tend to increase their focus on child participation. They are generally more appreciative of the significance and importance of the contributions of social support systems and/or the group of significant adults involved with the child.

The ICF-CY provides a multidimensional framework to develop a functional profile of the child. Its use enhances evidence-based clinical work by offering a tool that can be applied systematically – for a differentiated assessment, clarifying diagnoses, planning appropriate intervention for the individual child and for monitoring intervention post medical treatment. The ICF-CY is also compatible with the information processing theories currently employed to explain cognitive development, eg. the categorisation of specific mental functions such as attention, memory and higher-order cognition.

From a children's rights perspective, the ICF-CY profile provides information on which services and support have to be accessed in order to optimally develop the child's potential. The actual progress made in terms of service delivery can also be evaluated.

The ICF-CY is considered the **gold standard for research on child functioning** and validating instruments utilised for its assessment. Because disability is seen as a variation of human functioning, the basis for classification is not a child's clinical diagnosis, but her/his measure of health and functioning. The Child Functioning Module (CFM) was developed by UNICEF and the Washington Group of Disability Statistics (WGDS) for the improvement of data collection on disability. It is aligned with the UNCRPD and the ICF-CY. It has been approved as a low-cost general screening tool to be utilised in under-resourced communities.

**The ICF-CY system is included in the procedure for determining disability eligibility in three stages:**

- **medical examination:** Body functions (code b) and Body structures (code s);
- **functional assessmen:** Body functions (code b), Activities and Participation (code d), and Environmental factors (code e); and
- **needs assessment:** Environmental factors (code e).

**The use of the ICF system has been recommended for the allocation of disability grants in Namibia:**

There has been a general increase in the number of persons with disabilities in need of disability grants - from 20 509 in 2009 to 47 183 adults and 6 599 children under 16 years old (MGEPESW 2020). However, the number of those receiving disability grants may be far from precise as the definition of disability used in the policy framework of Namibia is not uniform, as it is being applied inconsistently by state doctors. There is a need to move from using the historical medical criteria of assessment to assessments that focus on needs that relate to functioning, as reflected in the International Classification of Functioning, Disability and Health (ICF).

Eligibility procedures in accordance with the Convention on the Rights of Persons with Disabilities and rights-based policy frameworks take into account that disability results from the interaction between individuals with impairments and environmental barriers and that access to services should primarily promote equal opportunities and participation.

In line with the UNCRPD, the ICF-CY is employed in a multidimensional, context-sensitive procedure to establish eligibility within educational systems in many different countries. This entails systemising information pertaining to the present situation of the child as well as her/his future situation as foreseen by stakeholders. The child and her/his parents participate at all levels of decision making.

**The ICF-CY also has particular value with regard to facilitating participation in education:**

"(K)nown critical factors related to the severity of [a] health condition that lead to restrictions in participation, as well as other factors quite unrelated to a health condition such as the child's relationship to the teacher, to other students, or the class, ICF-CY could provide the biopsychosocial framework to consider all these aspects in children and adolescents and provide new therapeutic tools and areas of intervention."

The ICF-CY provides a tool for appropriate intervention planning – whether functional impairments are the focus, or whether it entails adjustments to the child's context, or both. Divergent opinions are integrated into a set of goals, with the explicit contribution of the child themself as well as parents and/or other caregivers.

Apart from the challenge of applying such a comprehensive system, there is also some substantial criticism concerning the ICF conceptualisation and language. Specifically, having the two constructs 'activities' and 'participation' in one coding scheme without a clear distinction is seen by some to be problematic when in fact they could be used interchangeably. It has been proposed that 'Sleep' should also be listed in the Activities and Participation (d) categories in the Self-Care chapter, in addition to it being classified in the Body Functions component (as Sleep Functions). In the same way, Rest could be added as a method of relaxation to the category Recreation and Leisure. A distinction should also be made between 'play' and 'games' in the Recreation and Leisure category.

**The following have also been flagged as ongoing issues:**

- The granularity gap pertaining to relational interactions within the caregiving environment are also an issue.

- Codes reflecting variables related to parental psychological well-being, relational demographics and child care are not sufficiently detailed.

- Meaningful concepts associated with autism cannot readily be described by means of the ICF-CY system. For example, there is no agreement on whether stereotypies (stereotypic movement) should be described as a voluntary or involuntary movement reaction.

# 4 APPLICATION

## 4.1 Presence of health condition

The ICF is a **health classification system** and its use presumes that one or more health conditions are present, requiring the attention of involved professionals in terms of its implications for the child's functioning related to her/his developmental track.

### Table 1: Examples of components of functioning linked to health conditions

| HEALTH CONDITION | IMPAIRMENT | ACTIVITY LIMITATION | PARTICIPATION RESTRICTION |
|---|---|---|---|
| Leprosy | Loss of sensation of extremities | Difficulty in grasping objects | Stigma of leprosy leads to discrimination |
| Spinal Injury | Paralysis | Incapable of using public transport | Lack of accommodations in public transportation leads to isolation |
| Juvenile Diabetes | Pancreatic dysfunction | None, when controlled by medication | Does not attend school due to stereotypes about disease |

Classification systems serve as structures to guide intervention and to develop policies. Conducting research would not serve a purpose if a system to organise information in terms of categories was not permissible. Apart from the potential discriminatory effect of 'labelling' a person by means of a diagnosis, when used as a descriptor of a health condition it can be helpful, especially in relation to the social model.

Accessing intervention services often requires a diagnosis. A **formal diagnosis** is a prerequisite in applying for a disability grant. Service providers are often guided by health condition descriptors: particular conditions are linked to specific intervention protocols and therefore, as soon as the diagnosis is made, the intervention strategy becomes operational.

Having a 'name' for their child's health condition often helps to allay any feelings of uncertainty and powerlessness on the part of parents and/or caregivers in the face of the identification of the disability. It also offers a point of departure with regards to future intervention. Having

### Aims of classification

**There are five reasons why information pertaining to childhood disability is categorised:**

#### Identification and Intervention

It is not unusual that an identified condition is linked to an intervention suitable for addressing it appropriately.

#### Parental expectations

After assessment, parents usually have a need for information to get clarity on their child's issues and to be guided on services available in this regard.

#### Legal rights

Eligibility policies for service provision is based on classification, for example, qualifying for additional support, educational accommodation or a disability grant.

#### Equity

When the normative value of fairness guides decision making, the allocation of limited resources among children with disabilities will be informed by the nature and degree of needs associated with their respective situations.

#### Accountability

Data is required to set standards and to monitor programmes for effectiveness. Comparisons of systems are done on the basis of categorised information.

an honest and open discussion on the issue (often a diagnosis) and the way forward, can instil trust in the expertise and anticipated support of service providers.

Clinical diagnoses often remain permanent and fail to convey information together with the implications of immediate intervention. The **profiling of functional characteristics** however, has the advantage of reflecting problems with current functioning that have direct significance for the proposed intervention. Due to the dynamic nature of functional profiling, the implication of changes in functioning that may occur in time are recognised.

## 4.2 Key construct: Participation in life

**Participation** is a feeling of belonging and engagement, experienced by the individual in relation to being active in a certain context.

Participation is not the surroundings of a child. The child's subjective perception of what her/his life is like, is quality of life.

> The fact that there is a lift at school, so that the child can access the student common room, does not capture the experience of the time the child spends within the school (e.g., whether the child is actually doing the same things within the common room as the other students). (McConachie et al 2006: 1158)

It is advised that a child's functioning is assessed in **'authentic environments'** (rather than formal clinical settings), in which contextual (personal and environmental) factors set the scene or serve as the backdrop. Everyday life comprises different situations in which children function within a certain context (e.g. mealtimes, sleep, playing in the schoolyard).

**Life situations can be conceptualised by the three dimensions represented in the ICF-CY:**

**acts**

general and basic functional abilities that progressively mature (developmental aspects, such as speaking and learning);

**tasks**

typical activities that are purposefully executed (activities of daily living (ADL), for example eating, dressing and toileting); and

**societal involvement**

relationship with life areas through engagement (for example education, leisure and religion).

Engagement in early childhood settings, such as preschool, mostly includes child involvement in play activities, with peers, materials or teachers. Screening for challenges with engagement in the early childhood phase may reveal a need for special support. A pre-schooler's capacity for engagement is associated with cognitive and social competency.

A distinction is made between core engagement and developmental engagement, and both should be evaluated with regards to preschool activities:

- **Core engagement involves less complex behaviour and has a weak relation to chronological age, for instance the basic skill of giving attention; and**
- **Developmental engagement is behaviour related to multidimensional tasks and has a strong relation to chronological age, eg. communication skills.**

The caregiving and/or support system of young children with delays and disabilities has special significance - the child relies on others for assistance and support in activities and participation, not only due to immaturity but also due to development that is temporarily or permanently compromised. Consistency of support can differ from context to context. Assistance and support to a child is often routine at home, in comparison to out-of-home settings where it may not be consistently available or may not be available at all.

**Research points to the following associations:**

**the measure of physical support on the basis of the availability, accessibility and affordability of the environment, and personal independence; and**

**the measure of social support by means of inclusion through acceptance and accommodation, and participation frequency.**

**Provided that circumstances are favorable, children with SD [severe disabilities] can act autonomously within a social framework. With the psychological capacity to make choices and get networks to help them compensate for impaired physical capacity, they can obtain their goals. A good illustration is a child with severe disability who could not handle tools by himself but decided to create an animal from wood during craft class. After asking his personal assistant to get a piece of wood and begin sawing, the child leaned against the assistant and most likely viewed himself as fulling [sic] participating in that activity. Performance in itself does not necessarily refer to participation, while not performing does not necessarily mean that someone is not participating. Participation is also being in control. (Adolfsson et al 2014: 28) [insertion for clarity]**

## 4.3 Preparation and planning

The application of the ICF system should be planned systematically, and according to the ICF ethical guidelines. (Appendix 3)

The ICD-10 system and the ICF can be utilised concurrently. A child's health condition description ('diagnosis') may be helpful in selecting qualifiers concerning activities and participation.

### Guiding questions for planning

**Why is the ICF-CY to be employed?**
The purpose for using the system is determined.

**What information is required?**
In relation to this purpose, the ICF components that can provide the information that is sought are selected.

**How is the system to be applied?**
The methodology (including related issues such as the ethics involved) is structured.

**Where and when is it to be used?**
The setting(s) and the time line are planned.

**Who are the stakeholders?**
The participants are identified.

Because none of the categories were removed from the original ICF taxonomy, some categories do not apply to children. To manage the extensive number of ICF-CY categories without losing the benefit of the richness of detailed descriptions, core and code sets can be utilised.

Children, their parents and/or caregivers and service providers should participate in the assessment process. Self-reports of children on their functioning within real-life situations are useful, and should be encouraged as a primary source of information.

Due to the immaturity of infants and pre-schoolers, their parents and caregivers can serve as proxy. Contributions form part of the information used by the team of professionals who conduct the assessment. The ICF-CY conceptual framework provides a basis for multidisciplinary collaboration. Secondary sources of information can include:

- records,
- reports,
- direct measurements,
- observation,
- interviews and/or
- professional judgement.


Available information should be used as is. Qualifiers should be based on explicit information only, and not on inferences made.

Among the most relevant environmental factors may be the individuals from whom the coder obtains information (e.g. the mother for the child, the caregiver for a person with a disability). Information from the person providing assistance and support should be considered together with the information given directly by the person whenever possible, as well as with information obtained through clinical observation. The functioning profile should always start from the point of view of the individual being described representing the primary source of information. However, the functioning profile should also be as objective as possible, as a profile of functioning and health and not just the perception of health. For this reason, the final coding should blend the various sources of information in order to best approximate an impartial objective representation which nevertheless incorporates factors of importance to the person involved.

Basic knowledge on human growth and development, is a prerequisite to applying the ICF-CY. The ability to distinguish between typical and non-typical differences in developmental domains is also essential.

**Accurate code allocation** relies on interpretation of information according to developmental milestones – as maturity increases, expectations regarding the nature and/or level of involvement change.

## The importance of developmental milestones

With age, the importance of different life situations changes. For example, play for young children is comparable with education for adolescents and work for adults, depicted as human rights by the UN Convention on the Rights of Persons With Disabilities. For higher ages, however, play might include recreation and amusement and thus get another connotation than for lower ages.

For example, a household task such as Preparing meals (d630) could for a preschool child mean helping to set the table, whereas for a child 7–12 years, it could mean instead setting the table on one's own and helping with the cooking, and for a teenager, it could mean planning, cooking and serving the meal.

It seems natural to assume that the youngest children focus their volition and attention on acts having a low level of complexity and context specificity; for example, walking constitutes a developmental milestone for the youngest children but is performed automatically by older children in social contexts.

Another category related to developmental milestones is Communication (d3), which is a common feature of assessment. Communication includes a wide range of functions and skills, and the use of ICF-CY concepts could make it more specifically defined, for example, responding, speaking, writing messages and conversing. In addition, body functions such as articulation or fluency might be considered. For the youngest children, 'talking' or 'expressing needs and wishes' might be complex tasks that include participation, because such skills are actively used to interact with others in specific contexts.

In order to generate a valid profile of the child's mental functioning and learning capacity, users should have at least a basic understanding of the cognitive process (or information processing) in relation to the ICF-CY categories, and similarly, concerning the learning process.

## 4.4 Classification procedure

### The following procedure is suggested in the ICF-CY manual:

01 Peruse all available information and identify its relevance in terms of the four domains: Body functions, Body structures, Activities and Participation, and Environmental factors. (see Appendices 4 to 7)

02 Locate the chapter of the domain that is most applicable to the information considered.

03 Read the description of the 4-character code and give specific attention to relevant notes.

04 Check the inclusion / exclusion notes, and apply these to the code.

05 If applicable, decide whether the more detailed description – the respective codes of 5 or 6 digits – is appropriate.

06 Proceed to use the most suitable level code, but keep the exclusion / inclusion notes in mind.

07 Review available information and assign a value for the universal qualifier for the extent of impairment in body function / structure, activity limitation and participation restriction.

08 Assign qualifier codes to the different item levels.

09 Repeat the steps above for each manifestation of functioning, disability or health condition as reflected in the available information.

10 The procedure can be structured in three consecutive steps as shown in Table 2.

## Table 2: The ICF-CY classification procedure in 3 steps

| STEP 1: Define purpose of ICF-CY assessment | STEP 2: Obtain evidence from assessment outcomes | STEP 3: Code and scale with qualifiers |
|---|---|---|
| How does the child's mind and body function?<br><br>Chapters b1 – b8<br>Chapters s1 – s8 | • Standardised and criterion-referenced measures of cognition, perception, attention, sensation<br>• Visual and auditory tests<br>• Physical measurements<br>• Laboratory measures | • Standards scores, incl. percentile scores and ranks<br>• Descriptive terms<br>• Clinical judgment ratings |
| How does the child learn?<br><br>Chapter b1<br>Chapters d1 and d3 | • Standardised and criterion-referenced measures of learning, communication, academic achievement<br>• Problem-solving tasks<br>• Observations during learning<br>• Self, teacher, parent reports on functioning | • Standard scores, incl. percentile scores and ranks<br>• Descriptions<br>• Clinical judgment ratings |
| How does the child respond / adapt to situational demands?<br><br>Chapter d2 | • Problem-solving tasks<br>• Observation during everyday situations<br>• Self, teacher, parent reports on functioning | • Standard scores, incl. percentile scores and ranks<br>• Descriptions<br>• Clinical judgment ratings |
| How does the child's independence feature?<br><br>Chapters d4 – d6 | • Standardised and criterion-referenced measures of mobility, adaptive and independent behaviour<br>• Observation of daily tasks and activities | • Standard scores, incl. percentile scores and ranks<br>• Descriptions<br>• Clinical judgment ratings |
| What is the nature and level of the child's participation?<br><br>Chapters d7 – d9 | • Standardised and criterion-referenced measures of social relationships and behaviour<br>• Self, teacher, parent reports on participation<br>• Official records<br>• Observation | • Standard scores, incl. percentile scores and ranks<br>• Descriptions<br>• Clinical judgment ratings |
| What barriers / facilitators impact the child's functioning in her / his proximal environment?<br><br>Chapters e1 – e5 | • Standardised and criterion-referenced measures of physical, social and attitudinal environments<br>• Observation of child-environment interaction<br>• Photographic, video / audio material | • Standard scores, incl. percentile scores and ranks<br>• Descriptions<br>• Clinical judgment ratings |

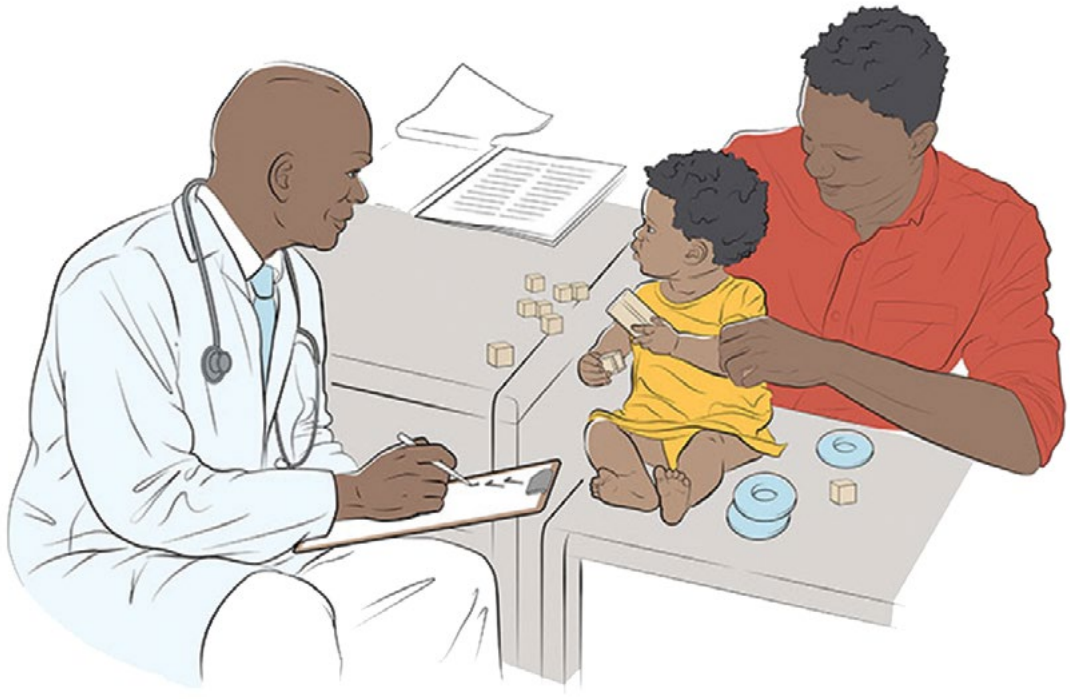
## 4.5 Coding system

The hierarchical coding system detailed in Appendices 4 to 7 at the end of this manual, with respect to Body Functions, Body Structures, Activities and Participation, and Environmental Factors, are explained in the following paragraphs.

### 4.5.1 Allocation of alphanumerical codes

- **The four components of functioning are each coded with an alphabetic letter, consistent with the theory and framework of functioning and disability:**

| COMPONENT | CODED |
|---|---|
| Body functions | b |
| Body structures | s |
| Activities and Participation | d |
| Environmental factors | e |



- **Each component is further divided into chapters or themes, eg. Body functions has 8 chapters: Mental functions (b1), Sensory functions and pain (b2), Voice and speech functions (b3), etc. Activities and Participation has 9 chapters and Environmental functions has 5.**

**These are coded with their respective numbers accordingly:**

| NO. | CHAPTERS | CODED |
|---|---|---|
| 8 | Body functions | b1 to b8 |
| 8 | Body structures | s1 to s8 |
| 9 | Activities and Participation | d1 to d8 |
| 5 | Environmental factors | e1 to e8 |

The d-categories are arranged according to increasing levels of difficulty and context. Learning (d1), General tasks and demands (d2) and Communication (d3) reflect general abilities and are therefore less situation specific. These activity (rather than participation) oriented categories are mostly applicable when assessing infants and pre-schoolers.

The mastery of basic skills (activities) is required as the foundation for societal involvement in later developmental phases (participation). The chapters comprising the component Activities (d1 to d4) and Participation (d5 to d9) are therefore demarcated as non-overlapping sets.

> [Y]oung children focus their attention and volition on acts that older children automatically perform. Since children at early ages are still learning how to cope with novel variations in the environment and have not yet automated tasks, such as walking up and down slopes or washing hands, they are more engaged in the performance of these tasks than elderly children usually are. (Adolfsson 2012: 591)

- **Each chapter consists of relevant domains that are categorised and defined. The level of detail provided is linked to the number of digits contained in the code: the more specific a description, the more numbers in its code.**

**Example: b5105.4**

| | |
|---|---|
| "b" | Body functions |
| "b5" | Functions of the digestive, metabolic and endocrine system |
| "b510" | Ingestion functions |
| "b5105" | Swallowing |
| "b5105.4" | Complete difficulty |

### 4.5.2 Provision of qualifiers

With a view to creating an individualised profile of functioning / disability, the use of qualifiers is most important. A generic qualifier describes the extent of the impairment or delay, activity limitation or participation restriction according to convention. Qualifiers are placed after a point following the alphanumerical digits indicating the functional domain concerned, as in the example above (b5105.4).

Use of any code should be accompanied by at least one qualifier. Without qualifiers codes have no inherent meaning (by default, WHO interprets incomplete codes as signifying the absence of a problem -xxx.00).

Qualifiers should be applied mindfully in relation to the component of functioning concerned.

- **Body functions (b) (see Appendix 4)**

The range of qualifiers to determine the scale and extent of an impairment or developmental delay is provided in Table 4.

- **Body structures (s) (see Appendix 5)**

Three qualifiers are used to describe an impairment of a body structure (i.e., anatomical part): extent, nature and localisation. (Table 3)

## Table 3: Qualifiers for Body structures

| IMPAIRMENT OF BODY STRUCTURES | | | | | |
|---|---|---|---|---|---|
| Qualifier 1: EXTENT | | Qualifier 2: NATURE | | Qualifier 3: LOCATION | |
| 0 | No impairment | 0 | no change in structure | 0 | more than one region |
| 1 | Mild | 1 | total absence | 1 | right |
| 2 | Moderate | 2 | partial absence | 2 | left |
| 3 | Severe | 3 | additional part | 3 | both sides |
| 4 | Complete | 4 | aberrant dimensions | 4 | front |
| | | 5 | discontinuity | 5 | back |
| | | 6 | deviating position | 6 | proximal |
| | | 7 | qualitative changes, including accumulation of fluid | 7 | distal |

## Table 4: Qualifiers for extent of impairment or developmental delay

| CODE | EXTENT OF IMPAIRMENT / DELAY* | DESCRIPTOR | PERCENTAGE RANGE | FREQUENCY AND INTENSITY |
|---|---|---|---|---|
| _xxx.0 | No | None, absent, negligible | 00 – 04 % | The child has no problem at any time or only very seldom. |
| _xxx.1 | Mild | Slight, low | 05 – 24 % | The problem is tolerable and present less than 25% of the time. In the last 30 days it hardly occurred. |
| _xxx.2 | Moderate | Medium, fair | 25 – 49 % | The problem is present 25% to 50% of the time, and its intensity sometimes interferes with the child's everyday life. |
| _xxx.3 | Severe | High, extreme | 50 – 95 % | The intensity of the problem is frequent to the extent that it interferes with daily life. It is present 50% to 95% of the time. |
| _xxx.4 | Complete | Total | 96 – 100 % | The problem occurs more than 95% of the time, and daily functioning is totally altered as a result of its intensity. |
| _xxx.8 | Not specified | | | |
| _xxx.9 | Not applicable | | | |

Two non-specific qualifiers are also available for coding in the following circumstances:
The qualifier "_xxx.8" is used to indicate "not specified", when insufficient information for encoding is obtainable. The qualifier "_xxx.9" is used to indicate "not applicable" in a situation in which a code is irrelevant or inappropriate. * The same qualifiers apply in the case of the occurrence of developmental delays.

- **Activities and Participation (d) (see Appendix 6)**

Activities relate to the whole child and may involve various bodily functions and structures. The immature child is still mastering skills associated with physical development.

### Interplay of physiological development and activities

Activities may relate to the interplay of multiple functions and structures. For example, speaking (d330) requires mental functions of language (b167), plus voice (b310), plus articulation (b320), all supported by the associated structures (s3). Essentials of walking (d450) include the combination of orientation (b114), balance (b235), control of voluntary movement (b760), muscle force (b730), tone (b735), mobility of joints (b710), structural support of bones (s7700), ligaments and tendons (s7701) – as well as enabling environmental factors such as well-built roads and footpaths. It is often possible to observe the specific body functions and the more complex related actions separately. In other cases, such as for many mental functions, the activity is the only way in which a body function may be assessed. For example, to evaluate attention functions (b140), the only available method is to observe the activity of focusing attention (d160).

The **Activities and Participation** component of functioning is assessed in terms of performance and/or capacityand the generic system of qualifiers are applied to these indicators.

**Performance** refers to the child's current environment. It is an expression of lived experience - the physical, social and attitudinal context in which the individual functions. It includes all forms of assistance that the child utilises in performing tasks or actions, whether assistive devices or personal help. The level of performance can however be context specific: e.g., depending on whether it takes place at home or at the ECD centre.

**Capacity** refers to the child's ability to execute a task or an action. The quantifier is an evaluation of the highest probable level of functioning that a person may reach in a given domain at a given moment. A naked assessment is required to be able to ascertain the true ability of the child ie., evaluating the child's ability to function without personal assistance or the use of assistive devices in a standardized environment. The individual is evaluated against a standardised assessment measure or the assumption of a general milieu applicable to all persons. (Appendix 1, questions on walking)

In some circumstances however, for example, when a medical device (such as a shunt) cannot be safely removed or when the action cannot be separated from the context (eg. household activities), an inference concerning capacity has to be made For children, the course of childhood development – tracked in terms of milestones – provides the baseline for assessment.

## Table 5: Qualifiers for Activities and Participation

| CODE | EXTENT OF DIFFICULTY |
|---|---|
| dxxx.0 | No difficulty |
| dxxx.1 | Mild |
| dxxx.2 | Moderate |
| dxxx.3 | Severe |
| dxxx.4 | Complete |
| dxxx.8 | not specified |
| dxxx.9 | not applicable |

**KEY:** dxxx.1st 2nd qualifier
first qualifier: level of Performance
second qualifier: level of Competence (i.e., Capacity)

| | QUALIFIER | |
|---|---|---|
| | First | Second |
| | Performance | Capacity |
| d4551.**14** | d4551.**1**_ | d4551._**4** |
| 3-year-old climbing stairs 5 | quite easy with mother's help mild restriction mental factors | otherwise unable complete limitation |

If one imagines natural environments as scenes for children's actions, each specific life situation is a drama that is going on. Several interacting factors affect the acting. Body functions and structures constitute the actor, acts mean to meet the demands set by the drama, and tasks are determined by the manuscript and the choreography. On stage, the scenery includes environmental factors as scene setters that may be barriers or facilitators for involvement in the drama. (Adolfsson 2011: 88)

**The gap between capacity and performance reflects the impact of current and uniform environments on performance and thus provides a useful guide as to what can be done to the environment of the individual to improve performance. (WHO 2007: 243)**

**Two kinds of gaps can occur:**

- Performance qualifier (first default digit numerical value) < Capacity qualifier (second default digit numerical value)

If **Capacity is greater than Performance**, it means that the child functions in a context in which there are barriers which hinder their abilities. Interventions can then be designed around removing these hindrances to allow for optimal functioning.

- Performance qualifier (first default digit numerical value) > Capacity qualifier (second default digit numerical value)

If **Capacity is less than Performance**, it means that the child functions in an enabling / facilitating environment. Interventions are designed around optimising their personal functioning competence.

Monitoring the gap between performance and capacity is one method of evaluating the efficiency of the intervention: a widening gap indicates increased functionality, while a narrowing gap shows a decrease in functioning.

- **Environmental factors (e) (see Appendix 7)**

The convention for scaling environmental factors as a barrier and/or facilitator is detailed in Table 6.

### Table 6: Environmental factor qualifiers

| CODE | QUALIFIER | DESCRIPTOR | PERCENTAGE RANGE |
|---|---|---|---|
| exxx.0 | No barrier | None, absent, negligible | 00 – 04 % |
| exxx.1 | Mild barrier | Slight, low | 05 – 24 % |
| exxx.2 | Moderate barrier | Medium, fair | 25 – 49 % |
| exxx.3 | Severe barrier | High, extreme | 50 – 95 % |
| exxx.4 | Complete barrier | Total | 96 – 100 % |
| exxx.8 | Barrier, not specified | | |
| | | | |
| exxx+0 | No facilitator | none, absent, negligible | 00 – 04 % |
| exxx+1 | Mild facilitator | slight, low | 05 – 24 % |
| exxx+2 | Moderate facilitator | medium, fair | 25 – 49 % |
| exxx+3 | Substantial facilitator | high, extreme | 50 – 95 % |
| exxx+4 | Complete facilitator | total | 96 – 100 % |
| exxx+8 | Facilitator, not specified | | |
| exxx.9 | Not applicable | | |

## Barriers

**Environmental barriers are risk factors for disability, and should be investigated as such.**

**Aspects to consider when assessing environmental barriers:**

- frequency of hindrance
- its degree
- its inevitability.

## Facilitators

**When an environmental factor improves performance, it is coded as a facilitator; when it lowers the level of performance, it is coded as a barrier.**

An important factor to consider is the sociocultural context in which the child is raised.

**Aspects to consider when determining environmental facilitators:**

- degree of accessibility of the resource
- its dependability / variability
- its quality.

While neither devices nor personal assistance alter the impairments, they may remove limitations on functioning in specific domains. This type of coding is particularly useful to identify how much the functioning of the individual would be limited without the assistive devices. (WHO 2002: 13)

## Barrier and facilitator simultaneously

**An environmental factor can serve as both facilitator and barrier.**

It is not infrequent that an environmental factor acts both as a facilitator and a barrier (e.g.,. a drug improving some symptoms but causing adverse effects; a mother providing support for a child in one area of life but at the same time preventing the development of his autonomy in interpersonal relations; specialised transportation services that facilitate using transportation, but are a barrier as their availability is limited and they prevent public transportation services from becoming fully accessible).

If the opposite effect is exerted on different aspects of functioning, it is possible to differentiate the opposing influence by attaching the environmental factor code to the affected category with the appropriate qualifier indicating its positive or negative effect (e.g., the mother facilitates self-care of the child but is a barrier to the personal interactions of that child). If the influence is observed on the same category, then one could either make an estimate of the final total effect that environmental factor has on the specific aspect of functioning, or repeating the category with a different qualifier measure.

In the ICF-CY, performance is the only possible indicator of participation. It is however suggested that participation is not only about taking part in what happens in everyday life situations, it is also about being engaged, being accepted, and having access. These aspects are not easily measured without asking the children or their caregivers about their opinion. To describe the impact of environmental factors on children's functioning, two qualifiers are applied to indicate facilitating factors and/or barriers.

### 4.5.3 Coding information from sources

It is essential that service providers apply the universal qualifier, as per convention, when sources of information are coded to ensure consistency of data. This will also ensure that professionals – whether therapists of a child's multidisciplinary team, or other stakeholders linked to the wellbeing of the child – share a frame of reference when interpreting a child's profile of functioning.

The convention is presented in Table 7.

**Table 7: Coding functional aspects described in sources of information**

| SOURCE OF INFORMATION | ICF-CY QUALIFIER | | | | |
|---|---|---|---|---|---|
| | 4 complete difficulty | 3 severe difficulty | 2 moderate difficulty | 1 mild difficulty | 0 no difficulty |
| • Standardised tests[2] | | | | | |
| Standard score Mean=100, SD2=15 | <40 | 41-55 | 56-70 | 71-85 | >86 |
| Scaled score Mean=10, SD=3 | <1 | 1 | 2-4 | 5-7 | >7 |
| T-score Mean=50, SD=10 | 0-10 | 11-20 | 21-30 | 31-40 | >41 |
| SD[3] unit below mean | >4 | 3-4 | 2-3 | 1-2 | 0 |
| • Clinical judgment | extreme variation from norm group or context | serious variation | moderate variation | slight variation | no variation |
| Reports, and collateral information | extremely low functioning | very low | moderately low | slightly below average | average or above average |

Caution should be exercised when applying results obtained from traditional intelligence testing. IQ scores are summative and only pertain to Intellectual functions (b117). In situations where a child's compromised mental functioning is of concern, it may be appropriate to rather use a subtest score for coding when the rationale of the subtest is consistent with the mental function category.

## 4.6 Core and code sets

An ICF-CY core set consists of the least number of categories practically possible, while simultaneously including a sufficient number of categories that comprehensively represent the functioning associated with a specific health condition.

**An example of a core set for cerebral palsy (CP) for the age group 0 to 5 years is available at:**

https://www.icf-research-branch.org/icf-core-sets/send/8-neurologicalconditions/253-brief-icfcs-cy-with-cp-below-6.

A **code set** is a condensed set of descriptors combined for a specific purpose. This simplification of the descriptors into a functional profile is particularly useful in discussion with parents and/or caregivers. A code set is established using the significant categories related to specific aspects of functioning. It may be useful in answering the question, "What are the main concerns of parents regarding their child's functioning?"

The online ICF browser is a useful tool for creating a code set that has a specific purpose or context, eg. early intervention or eligibility for social protection.

**The ICF browser is available at: https://apps.who.int/classifications/icfbrowser/**

**Three examples of code sets:**

## Everyday life situations (ELS) code sets

**Everyday Life Situations (ELS)** are understood as complex life areas of social involvement that include acts and tasks, such as mealtime or play time. A useful way to assess child functioning is through code sets developed for ELS.

The significant categories for ELS code sets for sleeping, mealtimes and play were identified using the Delphi method[4] together with the parents of six families with children in the age group 0 to 6 years, and professionals from five multidisciplinary teams involved with children with and without disabilities.

### Three ELS code sets

**Sleeping**
Sleep functions (b134), Changing basic body position (d410) and Support from (e310) and attitudes of immediate family (e410)

**Mealtimes**
Ingestion functions (b510), Other purposeful sensing (d120), Maintaining a body position (d415), Eating (d550) and drinking (d560)

**Play**
Engaging in play (d880) and Support from (e310) and attitudes of immediate family (e410)

**The ELS are sequences of actions that are functional within everyday contexts and directed towards goals that are meaningful for the child.**

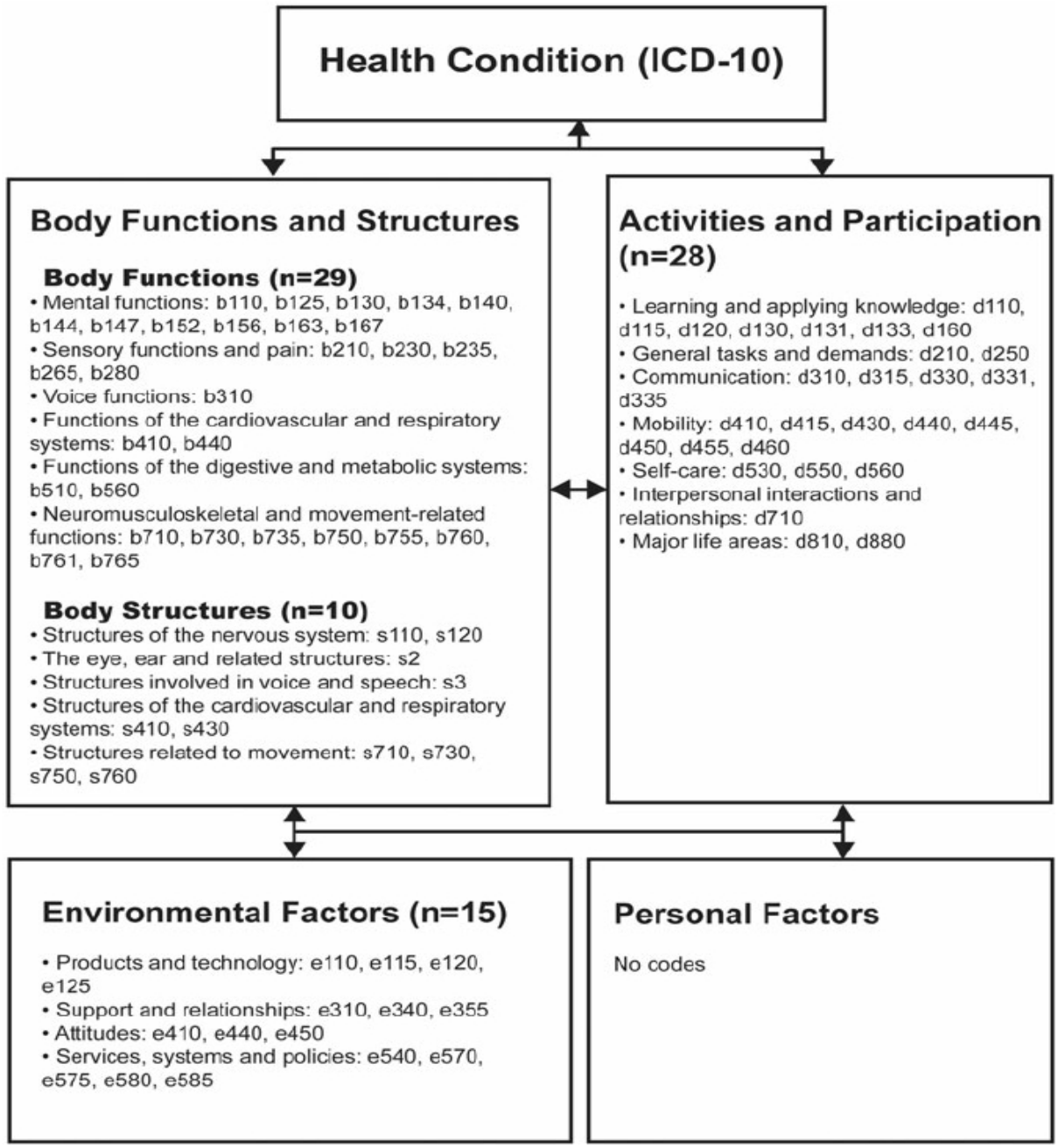
## Developmental code set

**Developmental code sets** determine expectations for the four developmental stages. The code sets for infancy and early childhood according to the ICF-CY categories are contained in Appendix 10.

## Early delay and disability (EDD) code set

The Delphi approach was also used to develop the **early delay and disability (EDD) code set.** Participants included a group of international professionals and pre-schoolers with developmental delays and disabilities. (Figure 6)

**Figure 6: The EDD code set**



## Autism spectrum code set

Three diagnostic tools for **Autism Spectrum Disorder (ASD)** were linked to the ICF-CY taxonomy by means of a step-wise integration of qualitative and quantitative data. The code set used to analyse the ADOS (Autism Diagnostic Observation Schedule), the ADI-R (Autism Diagnostic Interview Revised) and the CARS (Childhood Autism Rating Scale) is set out below.

### Autism spectrum code set

**Body functions and structures**
Mental functions (b1)

**Activities and Participation**
Learning and applying knowledge (d1); General tasks and demands (d2), Communication (d3); Self-care (d5); Interpersonal interactions (d7); Major life domains (d8); Community, social and civic life (d9)

**Environmental factors**
Support and relationships (e3); Attitudes (e4); Services, systems and policies (e5)

Optimal involvement in life experiences are the end-goal when interventions are planned for children with disabilities. For very young children this can be **Everyday Life Situations (ELS)** or developmental expectations. A holistic individualised profile is created with a view to render multidisciplinary habilitation services.

**The profile has two components:**

**Individual component:**
the body functions of the individual are considered as a means to address limitations in activity.

**Social component:**
the complete environmental context of the child is evaluated to be able to address participation restrictions.

The child's individualised profile is updated as they develop and intervention services are concurrently monitored for progress and possible revision if necessary.

# 5 CASE STUDIES

## 5.1 Case study: Anna, a 5-year-old girl

### Defining Intervention Expectations

**Anna, a 5-year-old girl**, attends a preschool. The staff reports that Anna spends almost all her time alone or with staff. Anna plays functional games (e.g., pretend-feeding a doll) and with toys, yet she is seldom involved with other children in her play. Anna's speech is difficult to understand because of articulation problems and restricted vocabulary. Her parents confirm these difficulties. Anna is referred to habilitation services by the preschool psychologist to define intervention priorities.

### Assessment and intervention planning for Anna

| Steps in intervention cycle | Body function / Body structure | Activity and participation | Environment |
|---|---|---|---|
| Assessment: problem description & explanation | b 16710 Mental functions of language, expression of language<br>b 1400 Sustaining attention<br>b 1402 Dividing attention<br>b 1403 Sharing attention<br>b 16710 Mental functions of language<br>b 7356 Muscle tone of all body | d 330 Speaking<br>d 3500-3504 Conversation<br>d 7504 Informal relationships with peers<br>d 330 Speaking<br>d 3500-3504 Conversation | e 325 Peers<br>e 330 People in positions of authority, e.g. teachers |
| Identification of intervention plan & goals | | d 330 Speaking<br>d 3500 Starting conversation<br>d 3503 Conversation with one person<br>d 3504 Informal relationships with peers | |
| Implementing intervention | | | e 125 Products and technology for communication<br>e 1300 Products and technology for education<br>e 325 Peers<br>e 330 Teachers<br>e 340 Personal assistant |
| Evaluating intervention outcomes | | Above codes on communication and social relationships | |

As can be seen in the table above, Anna's problems are primarily identified within the Activities and Participation component in terms of using spoken language; engaging in conversation with peers at preschool; starting, sustaining, and ending conversations; and lack of peer relations.

Barriers in the environment include the lack of attention and communication invitations to Anna by her peers, as well as the preschool' staff's lack of knowledge of how to set up communicative temptations involving peers.

Parents and preschool staff agree on a long-term goal - Anna's informal relationship with her peers - with the objectives of: focusing on speaking, starting conversations, and conversing with one person (a peer).

**Intervention methods are defined in terms of environmental factors and include:**

a) using iconic symbols and the walls of the preschool (e 125) to augment spoken messages, and

b) providing training material on communication to staff and parents (e 1300) to effect change in the communicative responsiveness of the communication partners.

These training materials are to be used to train staff (e 330) in the setting up of communication temptations involving Anna's peers and to train peers (e 325) to adjust their conversational approach with Anna. In addition, Anna is provided with a personal assistant (e 340) at preschool.

## 5.2 Case study: C, a 3-year-old girl

C was born following an uneventful pregnancy. She has a history of congenital heart problems, which were corrected in two surgeries early in life. She continues to have frequent upper respiratory and ear infections, which appear to have affected her hearing.

C and her mother live in an apartment in the centre of a large city and receive their medical care at a clinic in one of the city's hospitals. C's father left shortly after her birth and does not contribute financially to the family. C is cared for by a neighbour during the day while her mother works at a local store. When her mother works on the weekends, C and her siblings stay with their grandmother.

C is a serious child who does not smile or laugh easily. She spends much of her time alone in simple play with objects and does not interact much with other children. She likes things that make a noise when they are pushed or pulled and will play with them for long periods of time. Other than that, she is easily distracted. When her attention is not engaged, she is inclined to engage in body rocking.

She started walking only three months ago and is unable to climb stairs unless someone is holding her hand. She has a vocabulary of about 20 words that are intelligible, such as 'mine,' 'more,' 'block,' 'juice,' and a larger vocabulary that is unintelligible. Sitting on her mother's lap to be read a story is one of her favourite activities. She will point to familiar pictures but has difficulty learning the names of objects in the pictures.

Frequently, when her name is called, she does not respond and often seems unaware of people talking around her. The basis for these behaviours is unclear but may be due to hearing loss from frequent ear infections. An assessment at 24 months old revealed that her developmental level was equivalent to 17 months. Developmental delay was particularly evident in receptive and expressive language. A hearing assessment also revealed mild, bilateral hearing loss.

**Questions:**

1. Is the child or adolescent manifesting problems in body functions[1]?
2. Does the child or adolescent have problems of organ, limb or other body structures?[2]
3. Does the child or adolescent have problems executing tasks or actions?[3]
4. Does the child or adolescent have problems engaging in age appropriate life situations?[4]
5. Are there environmental factors[5] that restrict or facilitate the child's or adolescent's functioning?

## Body functions

**Chapter 1: Mental functions**

| | |
|---|---|
| b114 | Orientation functions |
| b1142 | Orientation to person |
| b11421 | Orientation to self |
| b11422 | Orientation to others |
| b126 | Temperament and personality functions |
| b1260 | Extraversion |
| b140 | Attention functions |
| b1400 | Sustaining attention |
| b144 | Memory functions |
| b1441 | Long-term memory |
| b156 | Perceptual functions |
| b1560 | Auditory perception |
| b167 | Mental functions of language |
| b1670 | Reception of language |
| b16701 | Reception of spoken language |
| b1671 | Expression of language |
| b16711 | Expression of spoken language |

**Chapter 2: Sensory functions and pain**

| | |
|---|---|
| b230 | Hearing functions |
| b2300 | Sound detection |

**Chapter 4: Functions of the cardiovascular, haematological, immunological, and respiratory system**

| | |
|---|---|
| b440 | Respiration functions |
| b450 | Additional respiratory functions |
| b4500 | Production of airway mucus |
| b4501 | Transportation of airways mucus |

**Chapter 7: Neuromusculoskeletal and movement-related functions**

| | |
|---|---|
| b765 | Involuntary movement functions |
| b7653 | Stereotypies and motor perseveration |

## Activities and Participation

**Chapter 1: Learning and applying knowledge**

| | |
|---|---|
| d131 | Learning through actions with objects |
| d1313 | Learning through symbolic play |
| d1314 | Learning through pretend play |

d133 Acquiring language
d1330 Acquiring single words or meaningful symbols
d1331 Combining words into phrases
d1332 Acquiring syntax

**Chapter 3: Communication**
d330 Speaking

**Chapter 4: Mobility**
d450 Walking
d455 Moving around
d4551 Climbing

**Chapter 7: Interpersonal interactions and relationships**
d710 Basic interpersonal interactions
d7104 Social cues in relationships
d71040 Initiating social interactions
d750 Informal social relationships
d7500 Informal relationships with friends

**Chapter 8: Major life areas**
d815 Preschool education
d8150 Moving into preschool educational programme or across levels
d880 Engagement in play
d8801 Onlooker play
d8802 Parallel play
d8803 Shared cooperative play

## Environmental factors

**Chapter 1: Products and technology**
e1152 Products and technology for play
e11520 General products and technology for play
e125 Products and technology for communication
e1251 Assistive products and technology for communication

**Chapter 3: Support and relationships**
e310 Immediate family
e340 Personal care providers and personal assistants
e355 Health professionals

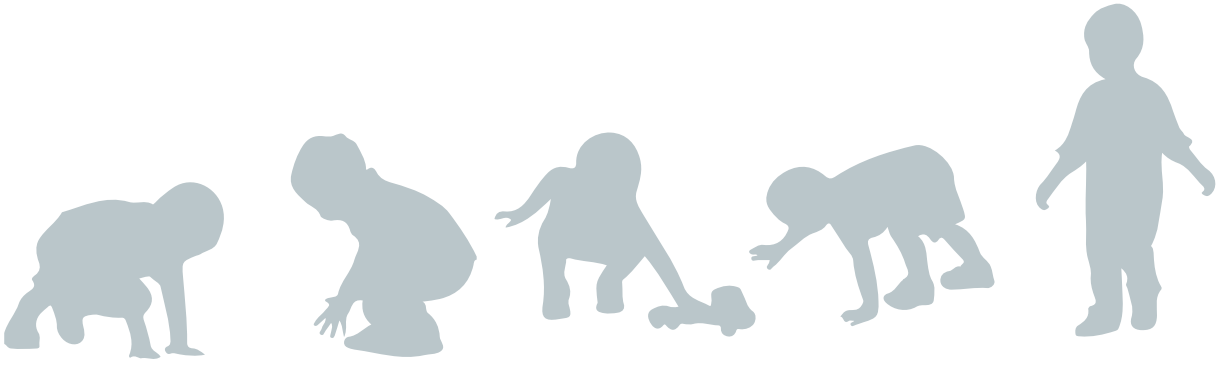
## 5.3 Core engagement and developmental engagement

**Analyse the following paragraph from an article by Adolfsson et al (2018: 3), reporting on research findings on engagement, according to the ICF-CY components:**

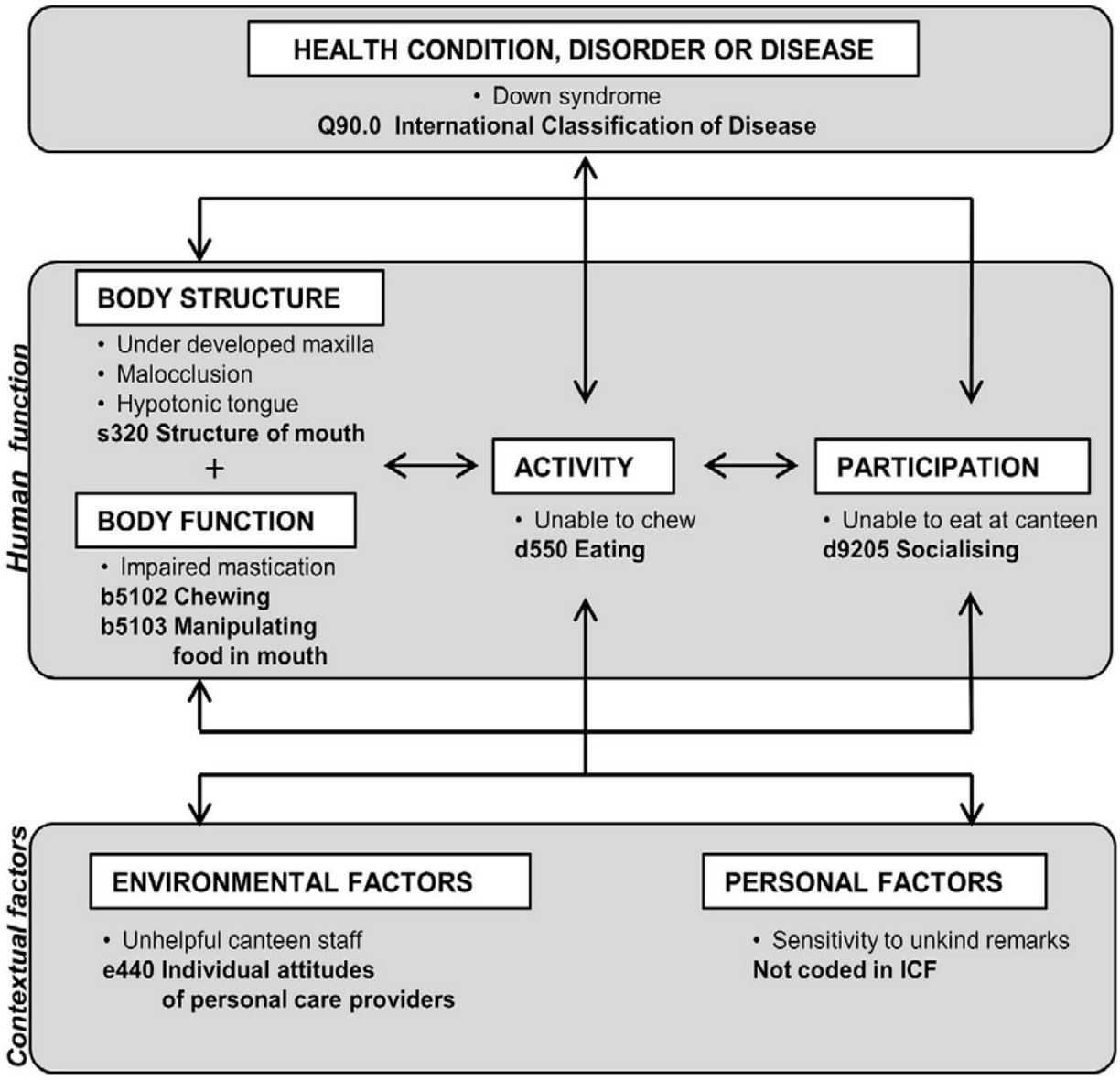
....additionally, the results revealed that children in need of special support tended to spend less time in developmental engagement, i.e., with complex tasks. Instead, they showed core engagement frequently when they were met by responsive teachers and when they were included in positive peer interactions.

Hyperactivity tended to have a negative influence on children's core engagement and developmental engagement, even though the association between hyperactivity and developmental engagement was a little bit weaker. Moreover, the results showed that quality of social interaction in preschool explained a large percentage of the total negative effect of hyperactivity on both types of engagement. Consequently, preschool children with hyperactivity showed a higher level of engagement when they were met by positive social interactions, which was especially strong for peer interactions.

This highlights the importance of the teacher's perception of children's engagement behavior, and knowledge of supporting child–child interaction in preschool, in order to improve engagement in everyday functioning, especially among children in need of special support. Both dimensions, core and developmental engagement, should be considered in the assessment of a child's engagement in preschool activities.



## 5.4 ICF Components: Down syndrome



## 5.5 Developmental perspective according to ICF-CY: Angelman syndrome[1]

**Bonanni et al (2009: s124-s125) reported their findings on the functioning of very young children with Angelman syndrome according to the ICF-CY taxonomy:**

Many items of the ICF-CY questionnaire, especially in the A&P and in the environmental factor components were providing information not otherwise available through the protocol evaluation. The relevant aspects of the profiles obtained are reassumed below.

### 0–3 age group

These children exhibited marked impairments of psychomotor and cognitive functions, with especially severe attention deficit. Vocalization is limited. Musculoskeletal functions are compromised in the tone, coordination and involuntary movement categories. Performance in most evaluable activities is compromised even with the presence of the care giver, while capacity is severely affected substantially in all domains. Specific difficulties are encountered both in the solitary play and when interacting with others, with continuous switch from one activity to the other.

### 4–6 age group

Also in these children the mental functions, especially attention and psychomotor functions, are severely compromised. Comprehension and production of non-spoken language emerges, while verbalization is still very limited. In these children, the activation of specific communication training substantially improves the communication capacity to a better performance level, but still the gap between comprehension, which is limited but present, and production, which is absent for spoken messages, is evident.

The musculoskeletal functions record the usual severe problem in coordination, but better stability is acquired with targeted physical therapy training. The changes brought about by the rehabilitation are recorded in the gap between capacity and performance in tasks requiring motor ability, which widens in attending regular rehabilitation, and narrows in those not following it.

Learning and applying knowledge is limited to very simple tasks, and always with the help of a care giver. Equally full help is required for interactions and self care.

## 5.6 Case study: Ayse,a 6-month-old girl

### Case A (WHO 2012: 62)

**Ayse is six months old** with normal growth, physical health and age-appropriate developmental milestones. Her mother leaves her in the care of her 12-year old sister while she goes to work in the fields,. Her mother returns to breastfeed her and returns to work. For safety reasons, Ayse is not allowed out of her crib and the children do not leave the house for 10 hours during the day. Ayse is not failing to thrive yet, but the family is becoming poorer and has limited access to food.

**Using the ICF:** Ayse is classified as having no impairments in body functions and structures, but severe restrictions in activities and participation, and severe barriers in environmental factors, i.e. basic care by adult and adequate food.

## 5.7 Case study: Elif, a 12-month-old girl

### Case B (WHO 2012: 62)

**Twelve-month-old Elif** was hospitalized for severe malnutrition, iron-deficiency anaemia and zinc deficiency. The medical history reveals that Elif has been breastfed from the start, although her mother had to force feed her after she refused to take supplemental solid foods. Elif is refusing to eat, is apathetic and uninterested in play. Her mother approaches her with anxiety and becomes very tense during feeding.

**Using the ICF:** Elif is classified as having impairments in body functions and structures, including malnutrition, anaemia and micronutrient deficiency. She is restricted in activities and participation because of her refusal to eat and her lack of interest in interactions and play. An environmental factor causing difficulty is the anxious and tense relationship of her mother. All these components require intervention.

## 5.8 Case study: Hakim, a 3-year-old boy

### Case C (WHO 2012: 62-63)

**Hakim** is brought to a community-based rehabilitation centre by his grandmother. He is a 3-year-old child with spastic paraplegia due to prematurity and intracranial haemorrhage. He is unable to bear weight or crawl, but can sit up in his wheelchair. He uses his hands to play with a home-made rattle and can feed himself effectively with a spoon. Hakim uses two-word sentences to make his needs understood by his caregivers. He is often brought to the village play area where his siblings and other friends wheel him to participate in hide and seek and tag games.

**Using the ICF:** Hakim is classified as having impairments in neuromusculoskeletal and movement-related body functions (impairment in lower half of body muscle power and tone due to paraplegia) and impairment in the central nervous system body structures, due to intracranial haemorrhage. Because he is unable to crawl or walk, he has complete difficulty in activities without caregiver and wheelchair assistance; other areas of developmental activity are unaffected. He has mild difficulty in participating in play, because he is often encouraged to participate by his caregivers, siblings, and others in the community.

The environment does not present barriers, as he has access to caregivers who promote his physical and mental health, development and learning. They provide access to CBR, which is present in the community, and he has technological assistance in the form of a wheelchair.

## 5.9 Developmental delays

**Analyse the comprehensive definition of developmental delay presented in the WHO and UNICEF discussion paper on ECD and disability, in relation to the ICF-CY taxonomy:**

### Developmental Delay:

Developmental delay refers to children who experience significant variation in the achievement of expected milestones for their actual or adjusted age. Developmental delays are measured using validated developmental assessments and may be mild, moderate or severe. Developmental delays are caused by poor birth outcomes, inadequate stimulation, malnutrition, chronic ill health and other organic problems, psychological and familial situations, or other environmental factors. While developmental delay may not be permanent, it can provide a basis for identifying children who may experience a disability. This further emphasizes the importance of early identification to commence timely interventions with family involvement, aimed at preventing delays, promoting emerging competencies and creating a more stimulating and protective environment.

## 5.10 Diagnosis

**Unpack the construct "diagnosis" according to the biopsychosocial model.**

## 5.11 Variability in interaction between functioning and environmental factors

**Read the text on functioning and environmental factors on pages 20, 25 and 43 (Interaction between health condition and environmental factors; The child within the family; and Interplay of physiological development and Activities) and discuss the following statement: The complexity of the interaction between functioning and environmental factors can vary.**

## 5.12 Albinism

In the case of albinism, a child will look different from most schoolchildren in Eastern and Southern Africa and will often have associated visual impairment – but it is the stigma and abuse of others that largely creates the disability and makes parents fearful to send their child to school. (Education Development Trust & UNICEF 2016: 36)

**Apply the ICF-CY model of functioning to the following research on albinism:**

Lund, P.M. & Taylor, J.S. 2008. Lack of adequate sun protection for children with oculocutaneous albinism in South Africa. BMC Public Health 8(225): 1-8. doi: 10.1186/1471-2458-8-225

## 5.13 Activities and Participation

**Applying the ICF-CY model, make a distinction between activity limitation and participation restriction and comment on the interaction.**

An eight year old boy encountered during research in Rwanda was left handed but the teacher forced him to use his right hand even though it was physically impaired, as there are entrenched attitudes that the right hand is correct for writing, and left hand writers are therefore stigmatised. Not only is the boy facing two types of stigma, but being forced to write with his right hand was further inhibiting his education because he found it so difficult to write. (Education Development Trust & UNICEF 2016: 66)

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# END NOTES

[1]The same qualifiers apply in the case of the occurrence of developmental delays (WHO 2007: xx).

[2]The statistical normal distribution appears in Appendix 8.

[3]Standard deviation

[4]For information on the method, see Adolfsson (2011: 23-24).

[5]"Body functions are the physiological functions of body systems (including psychological functions)" (p 10). Mental and/or psychological functions are included, because "'[b]ody refers to human organism as a whole, including the brain" (p 228). These functions are evaluated according to the developmental norm for humans.

[6]"Body structures are anatomical parts of the body such as organs, limbs and their components" (p 11). The statistical norm for humans is used as the standard.

[7]"Activity is the execution of a task or action by an individual" / "Activity limitations are difficulties an individual may have in executing activities" (p 12). "These may range from a slight to a severe deviation in terms of quality or quantity in executing the activity in a manner or to the extent that is expected of people without the health condition" (p 229).

[8]"Participation is the involvement in a life situation" / "Participation restrictions are problems an individual may experience in involvement in life situations" (p 12). "The presence of a participation restriction is determined by comparing an individual's participation to that which is expected of an individual without a disability in that culture or society" (p 229).

[9]"Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives" (p 15).

# APPENDIX 1

## CHILD FUNCTIONING MODULE (CFM) (UNICEF / WASHINGTON GROUP OF DISABILITY STATISTICS 2016)

The link to the manual with full instructions on administration is:
https://data.unicef.org/resources/module-on-child-functioning-manual-for-interviewers/

The link to the questionnaires is:
https://data.unicef.org/resources/module-child-functioning/

| CHILD FUNCTIONING (AGE 2-4) | | CF |
|---|---|---|
| **CF1**. I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT DIFFICULTIES YOUR CHILD MAY HAVE.<br><br>DOES (*NAME*) WEAR GLASSES? | Yes.....1<br>No.....2 | <br><br>2 CF3 |
| **CF2**. WHEN WEARING HIS/HER GLASSES, DOES (*NAME*) HAVE DIFFICULTY SEEING?<br><br>WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | <br>No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | <br>1 CF4<br>2 CF4<br>3 CF4<br>4 CF4 |
| **CF3**. DOES (*NAME*) HAVE DIFFICULTY SEEING?<br><br>WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | <br>No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF4**. DOES (*NAME*) USE A HEARING AID? | Yes.....1<br>No.....2 | <br>2 CF6 |
| **CF5**. WHEN USING HIS/HER HEARING AID, DOES (*NAME*) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC?<br><br>WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | <br>No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | <br>1 CF7<br>2 CF7<br>3 CF7<br>4 CF7 |
| **CF6**. DOES (*NAME*) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC?<br><br>WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | <br>No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF7**. DOES (*NAME*) USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING? | Yes.....1<br>No.....2 | <br>2 CF10 |

| | | |
|---|---|---|
| **CF8**. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*NAME*) HAVE DIFFICULTY WALKING?<br><br>WOULD YOU SAY (*NAME*) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF9**. WITH HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*NAME*) HAVE DIFFICULTY WALKING?<br><br>WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | 1□CF11<br>2□CF11<br>3□CF11<br>4□CF11 |
| **CF10**. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*NAME*) HAVE DIFFICULTY WALKING?<br><br>WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF11**. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*NAME*) HAVE DIFFICULTY PICKING UP SMALL OBJECTS WITH HIS/HER HAND?<br><br>WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF12**. DOES (*NAME*) HAVE DIFFICULTY UNDERSTANDING YOU?<br><br>WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF13**. WHEN (*NAME*) SPEAKS, DO YOU HAVE DIFFICULTY UNDERSTANDING HIM/HER?<br><br>WOULD YOU SAY YOU HAVE: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF14**. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*NAME*) HAVE DIFFICULTY LEARNING THINGS?<br><br>WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF15**. COMPARED WITH CHILDREN OF THE SAME AGE, DOES (*NAME*) HAVE DIFFICULTY PLAYING?<br><br>WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF16**. COMPARED WITH CHILDREN OF THE SAME AGE, HOW MUCH DOES (*NAME*) KICK, BITE OR HIT OTHER CHILDREN OR ADULTS?<br><br>WOULD YOU SAY: NOT AT ALL, THE SAME OR LESS, MORE OR A LOT MORE? | Not at all.....1<br>The same or less.....2<br>More.....3<br>A lot more.....4 | |

| CHILD FUNCTIONING (AGE 5-17) | | CF |
|---|---|---|
| **CF1**. I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT DIFFICULTIES YOUR CHILD MAY HAVE.<br><br>DOES (*NAME*) WEAR GLASSES OR CONTACT LENSES? | Yes.....1<br>No.....2 | <br><br>2⇨CF3 |
| **CF2**. WHEN WEARING HIS/HER GLASSES OR CONTACT LENSES, DOES (*NAME*) HAVE DIFFICULTY SEEING?<br><br>WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | 1⇨CF4<br>2⇨CF4<br>3⇨CF4<br>4⇨CF4 |
| **CF3**. DOES (*NAME*) HAVE DIFFICULTY SEEING?<br><br>WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF4**. DOES (*NAME*) USE A HEARING AID? | Yes.....1<br>No.....2 | <br>2⇨CF6 |
| **CF5**. WHEN USING HIS/HER HEARING AID, DOES (*NAME*) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC?<br><br>WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | 1⇨CF7<br>2⇨CF7<br>3⇨CF7<br>4⇨CF7 |
| **CF6**. DOES (*NAME*) HAVE DIFFICULTY HEARING SOUNDS LIKE PEOPLES' VOICES OR MUSIC?<br><br>WOULD YOU SAY (*NAME*) HAS: NO DIFFICULTY, SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF7**. DOES (*NAME*) USE ANY EQUIPMENT OR RECEIVE ASSISTANCE FOR WALKING? | Yes.....1<br>No.....2 | <br>2⇨CF12 |
| **CF8**. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*NAME*) HAVE DIFFICULTY WALKING 100 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 1 FOOTBALL FIELD. [OR INSERT COUNTRY SPECIFIC EXAMPLE].<br><br>WOULD YOU SAY (*NAME*) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | <br>3⇨CF10<br>4⇨CF10 |
| **CF9**. WITHOUT HIS/HER EQUIPMENT OR ASSISTANCE, DOES (*NAME*) HAVE DIFFICULTY WALKING 500 YARDS/METERS ON LEVEL GROUND? THAT WOULD BE ABOUT THE LENGTH OF 5 FOOTBALL FIELDS. [OR INSERT COUNTRY SPECIFIC EXAMPLE].<br><br>WOULD YOU SAY (*NAME*) HAS: SOME DIFFICULTY, A LOT OF DIFFICULTY OR CANNOT DO AT ALL? | Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |

| | | |
|---|---|---|
| **CF10**. With his/her equipment or assistance, does (*NAME*) have difficulty walking 100 yards/meters on level ground? That would be about the length of 1 football field. [Or insert country specific example].<br><br>Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | 3⇨CF14<br>4⇨CF14 |
| **CF11**. With his/her equipment or assistance, does (*NAME*) have difficulty walking 500 yards/meters on level ground? That would be about the length of 5 football fields. [Or insert country specific example].<br><br>Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | 1⇨CF14<br>2⇨CF14<br>3⇨CF14<br>4⇨CF14 |
| **CF12**. Compared with children of the same age, does (*NAME*) have difficulty walking 100 yards/meters on level ground? That would be about the length of 1 football field. [Or insert country specific example].<br><br>Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | 3⇨CF14<br>4⇨CF14 |
| **CF13**. Compared with children of the same age, does (*NAME*) have difficulty walking 500 yards/meters on level ground? That would be about the length of 5 football fields. [Or insert country specific example].<br><br>Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF14**. Does (*NAME*) have difficulty with self-care such as feeding or dressing him/herself?<br><br>Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF15**. When (*NAME*) speaks, does he/she have difficulty being understood by people inside of this household?<br><br>Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |

| | | |
|---|---|---|
| **CF16**. When (*NAME*) speaks, does he/she have difficulty being understood by people outside of this household?<br><br>Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF17**. Compared with children of the same age, does (*NAME*) have difficulty learning things?<br><br>Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF18**. Compared with children of the same age, does (*NAME*) have difficulty remembering things?<br><br>Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF19**. Does (*NAME*) have difficulty concentrating on an activity that he/she enjoys doing?<br><br>Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF20**. Does (*NAME*) have difficulty accepting changes in his/her routine?<br><br>Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF21**. Compared with children of the same age, does (*NAME*) have difficulty controlling his/her behaviour?<br><br>Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF22**. Does (*NAME*) have difficulty making friends?<br><br>Would you say (*NAME*) has: no difficulty, some difficulty, a lot of difficulty or cannot do at all? | No difficulty.....1<br>Some difficulty.....2<br>A lot of difficulty.....3<br>Cannot do at all.....4 | |
| **CF23**. How often does (*NAME*) seem very anxious, nervous or worried?<br><br>Would you say: daily, weekly, monthly, a few times a year or never? | Daily.....1<br>Weekly.....2<br>Monthly.....3<br>A few times a year.....4<br>Never.....5 | |
| **CF24**. How often does (*NAME*) seem very sad or depressed?<br><br>Would you say: daily, weekly, monthly, a few times a year or never? | Daily.....1<br>Weekly.....2<br>Monthly.....3<br>A few times a year.....4<br>Never.....5 | |

# APPENDIX 2

## MOST ADDITIONS TO THE ACTIVITIES AND PARTICIPATION (d) CHAPTERS OF THE ICF-CY

- **d1 Learning and applying knowledge**

*Purposeful sensory experiences*

d120 Other purposeful sensing
- d1200 Mouthing
- d1201 Touching
- d1202 Smelling
- d1203 Tasting

*Basic learning*

d131 Learning through actions with objects
- d1310 Learning through simple actions with a single object
- d1311 Learning through actions by relating two or more objects
- d1312 Learning through actions by relating two or more objects with regard to specific features
- d1313 Learning through symbolic play
- d1314 Learning through pretend play

d132 Acquiring information

d133 Acquiring language
- d1330 Acquiring single words or meaningful symbols
- d1331 Combining words into phrases
- d1332 Acquiring syntax

d134 Acquiring additional language

d137 Acquiring concepts
- d1370 Acquiring basic concepts
- d1371 Acquiring complex concepts

d140 Learning to read
- d1400 Acquiring skills to recognize symbols including figures, icons, characters, alphabet letters and words
- d1401 Acquiring skills to sound out written words
- d1402 Acquiring skills to understand written words

d145 Learning to write
- d1450 Acquiring skills to use writing implements
- d1451 Acquiring skills to write symbols, characters and alphabet
- d1452 Acquiring skills to write words and phrases

d150 Learning to calculate
- d1500 Acquiring skills to recognize numerals, arithmetic signs and symbols
- d1501 Acquiring skills of numeracy such as counting and ordering
- d1502 Acquiring skills in using basic operations

*Applying knowledge*

d160 Focusing attention
- d1600 Focusing attention on the human touch, face and voice
- d1601 Focusing attention to changes in the environment

d161 Directing attention
d163 Thinking
d1630 Pretending
d1631 Speculating
d1632 Hypothesizing
d166 Reading
d1660 Using general skills and strategies in the reading process
d1661 Comprehending written language
d170 Writing
d1700 Using general skills and strategies in the writing process
d1701 Using grammatical and mechanical conventions in written compositions
d1702 Using general skills and strategies to complete compositions
d172 Calculating
d1720 Using simple skills and strategies of the calculation process
d1721 Using complex skills and strategies of the calculation process

- **d2 General tasks and demands**

d210 Undertaking a single task
d2104 Completing a simple task
d2105 Completing a complex task
d230 Carrying out daily routine
d2300 Following routines
d2304 Managing changes in daily routine
d2305 Managing one's time
d2306 Adapting to time demands
d250 Managing one's own behaviour
d2500 Accepting novelty
d2501 Responding to demands
d2502 Approaching persons or situations
d2503 Acting predictably
d2504 Adapting activity level

- **d3 Communication**

*Communicating - receiving*
d310 Communicating with – receiving – spoken messages
d3100 Responding to the human voice
d3101 Comprehending simple spoken messages
d3102 Comprehending complex spoken messages
*Communicating – producing*
d331 Pre-talking
d332 Singing

- **d4 Mobility**

*Changing and maintaining body position*
d410 Changing basic body position
d4107 Rolling over

d415 Maintaining a body position
d4155 Maintaining head position
d446 Fine foot use
*Walking and moving*
d455 Moving around
d4555 Scooting and rolling
d4556 Shuffling
*Moving around using transportation*
d470 Using transportation
d4708 Using humans for transportation

- **d5 Self-care**

d520 Caring for body parts
d5205 Caring for nose
d530 Toileting
d5300 Regulating urination
d53000 Indicating need for urination
d53001 Carrying out urination properly
d5301 Regulating defecation
d53010 Indicating need for defecation
d53011 Carrying out defecation appropriately
d550 Eating
d5500 Indicating a need for eating
d5501 Carrying out eating appropriately
d560 Drinking
d5600 Indicating need for drinking
d5601 Carrying breast feeding
d5602 Carrying out feeding from bottle
d570 Looking after one's health
d5702 Maintaining one's health
d57020 Managing medications and following health advice
d57021 Seeking advice or assistance from caregivers or professionals
d57022 Avoiding risks of abuse of drugs or alcohol
d571 Looking after one's safety

- **d6 Domestic life**

*Household tasks*
d630 Preparing meals
d6302 Helping prepare meals
d640 Doing housework
d6406 Helping to housework
*Caring for household objects and assisting others*
d650 Caring for household objects
d6507 Helping to care for household objects
d660 Assisting others
d6606 Helping in assisting others

- **d7 Interpersonal interactions and relationships**

*General interpersonal interactions*

d710 Basic interpersonal interactions

d7104 Social cues in relationships

d71040 Initiating social interactions

d71041 Maintaining social interactions

d7106 Differentiation of familiar persons

- **d8 Major life areas**

*Education*

d815 Preschool education

d8150 Moving into preschool educational programme or across levels

d8151 Maintaining educational preschool programme

d8152 Progressing in preschool educational programme

d8153 Terminating preschool educational programme

d816 Preschool life and related activities

d820 School education

d8200 Moving into educational programme or across levels

d8201 Maintaining educational programme

d8202 Progressing in educational programme

d8203 Terminating educational programme or school levels

d880 Engagement in play

d8800 Solitary play

d8801 Onlooker play

d8802 Parallel play

d8803 Shared cooperative play

- **d9 Community, social and civic life**

d910 Community life

d9103 Informal community life

# APPENDIX 3

## ICF ETHICAL GUIDELINES (WHO 2001: 244-245)

1. The inherent value and autonomy of each individual should be respected by the way the ICF is employed.

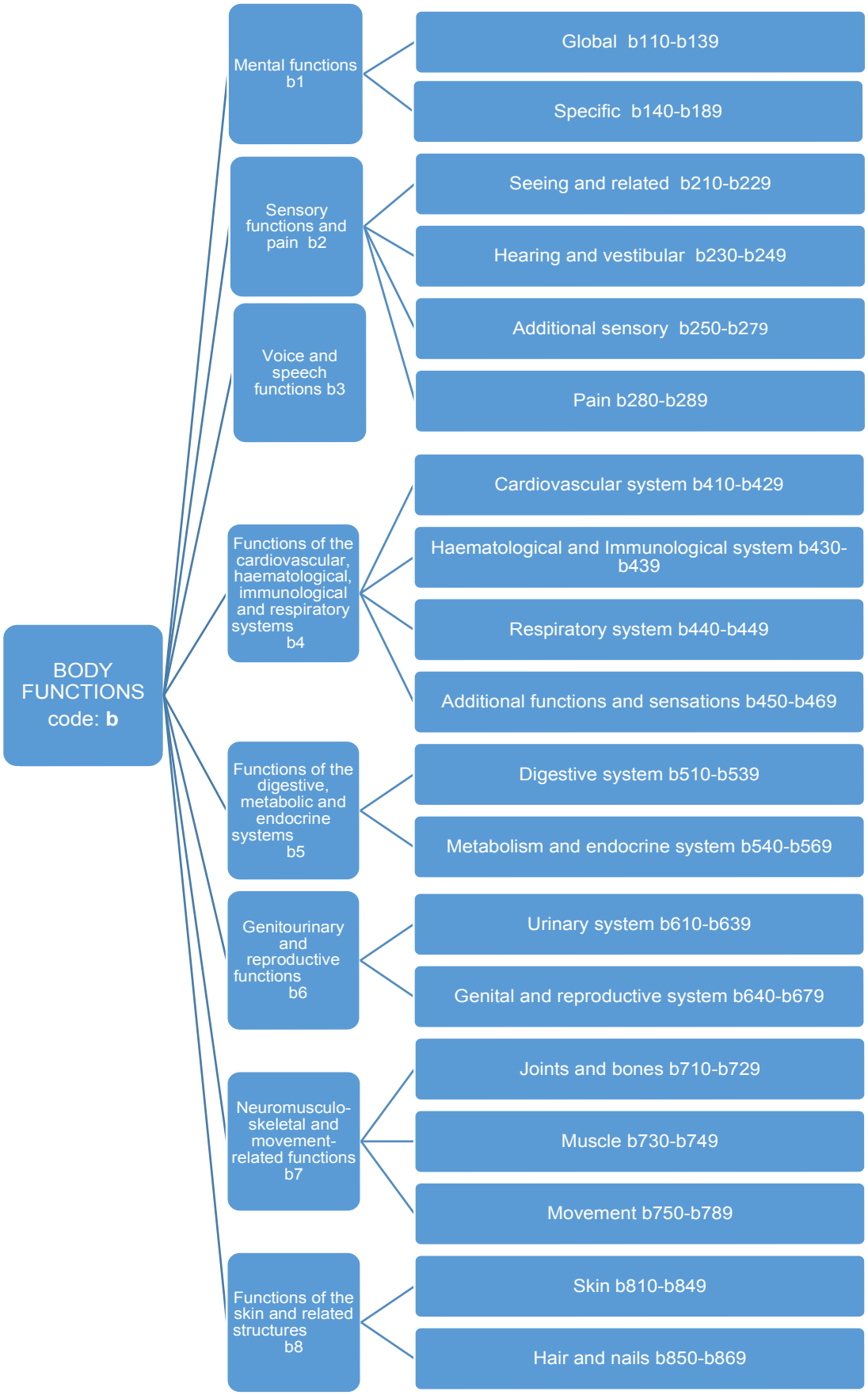
2. It should not be used to label an individual or to identify her / him solely according to one or more disability category.

3. In clinical settings, the system should always be used with the informed consent of the person whose functioning is assessed, or an advocate in the case of a person who is restricted to participate due to limitations to cognitive functioning.

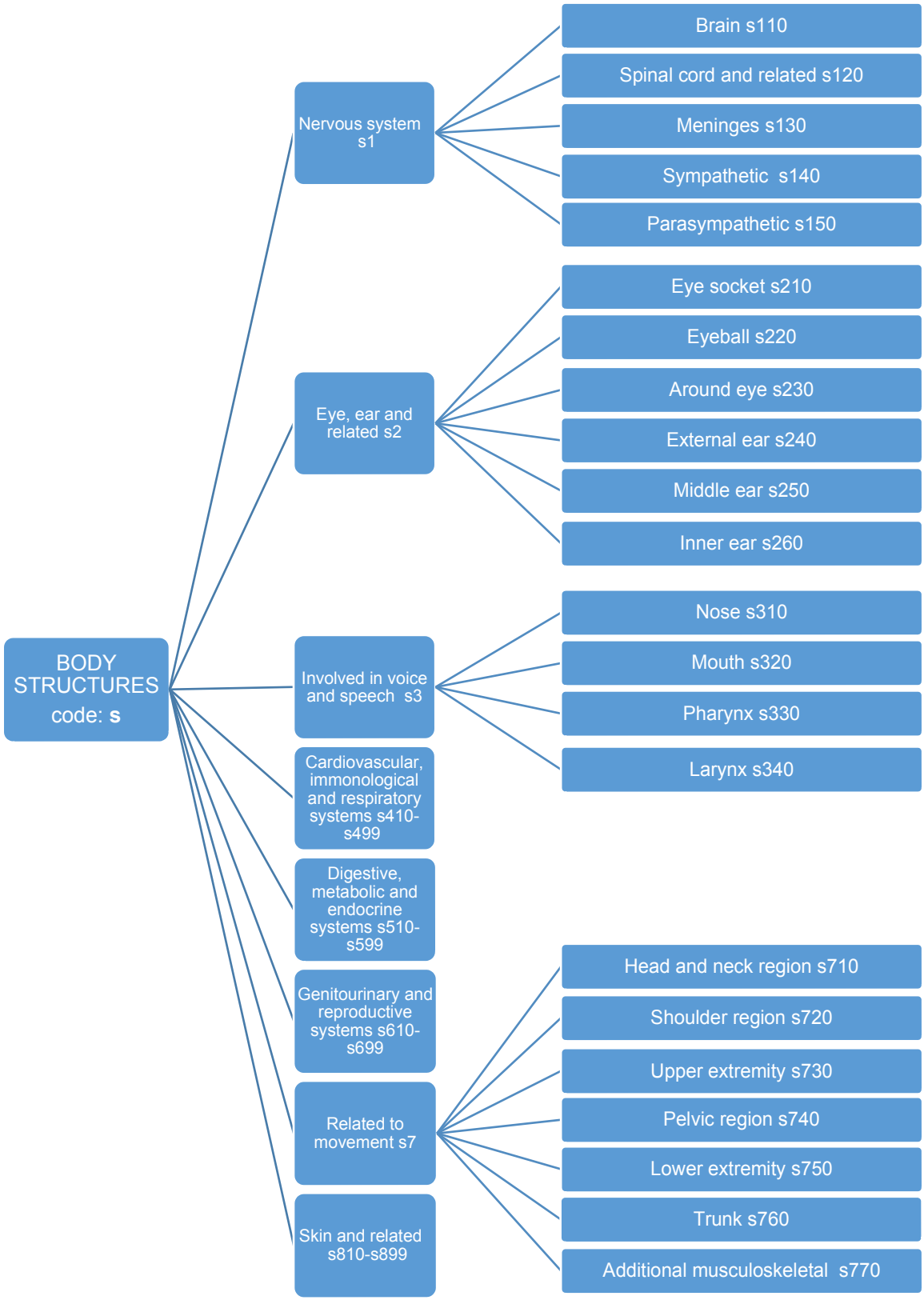
4. The information used for coding is considered of a personal nature and should therefore be managed according to accepted principles of confidentiality.

5. In clinical practice the individual or her / his advocate should be given a full explanation of the purpose of employing the ICF and its appropriateness should be discussed.

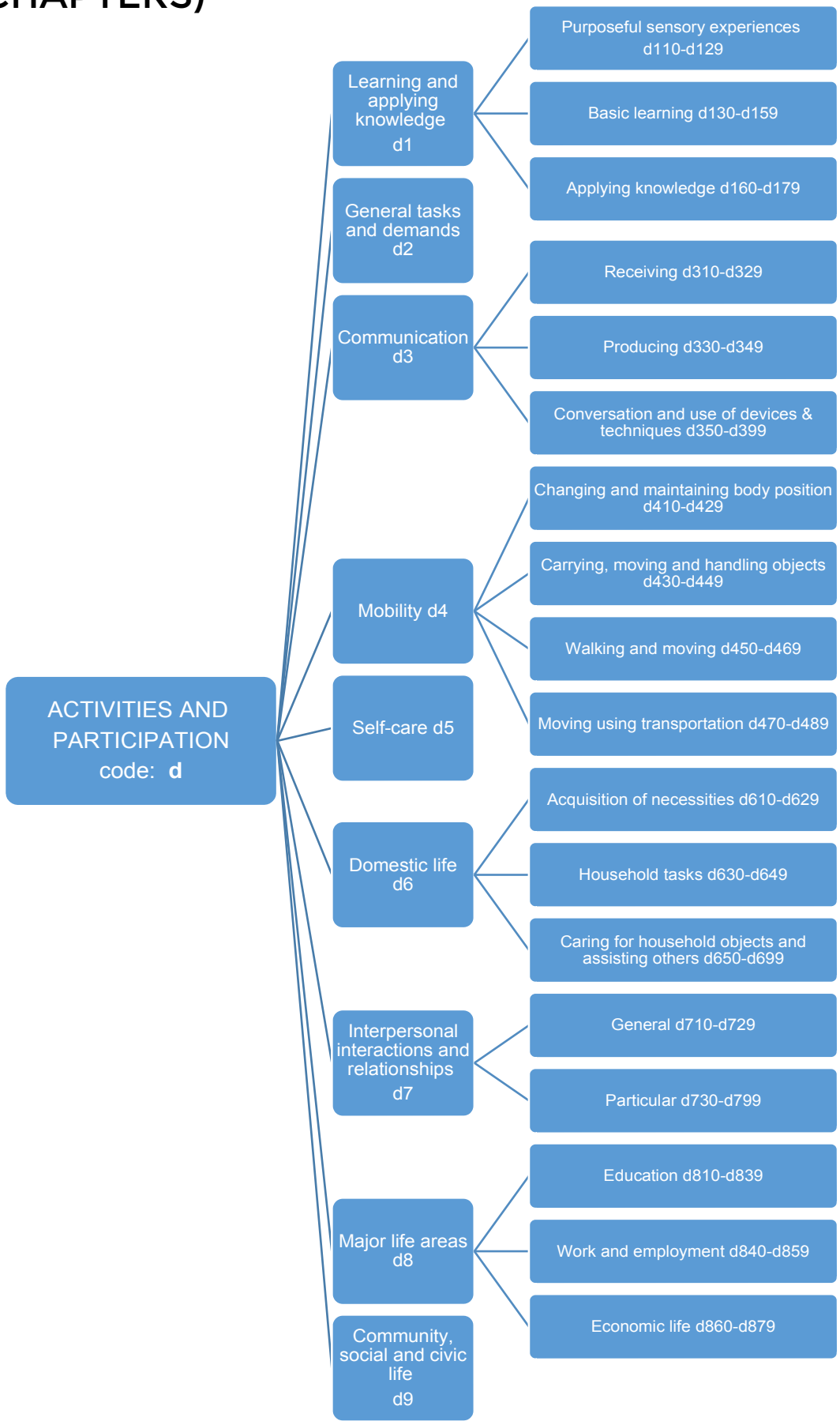
# APPENDIX 4: BODY FUNCTIONS (b CHAPTERS)



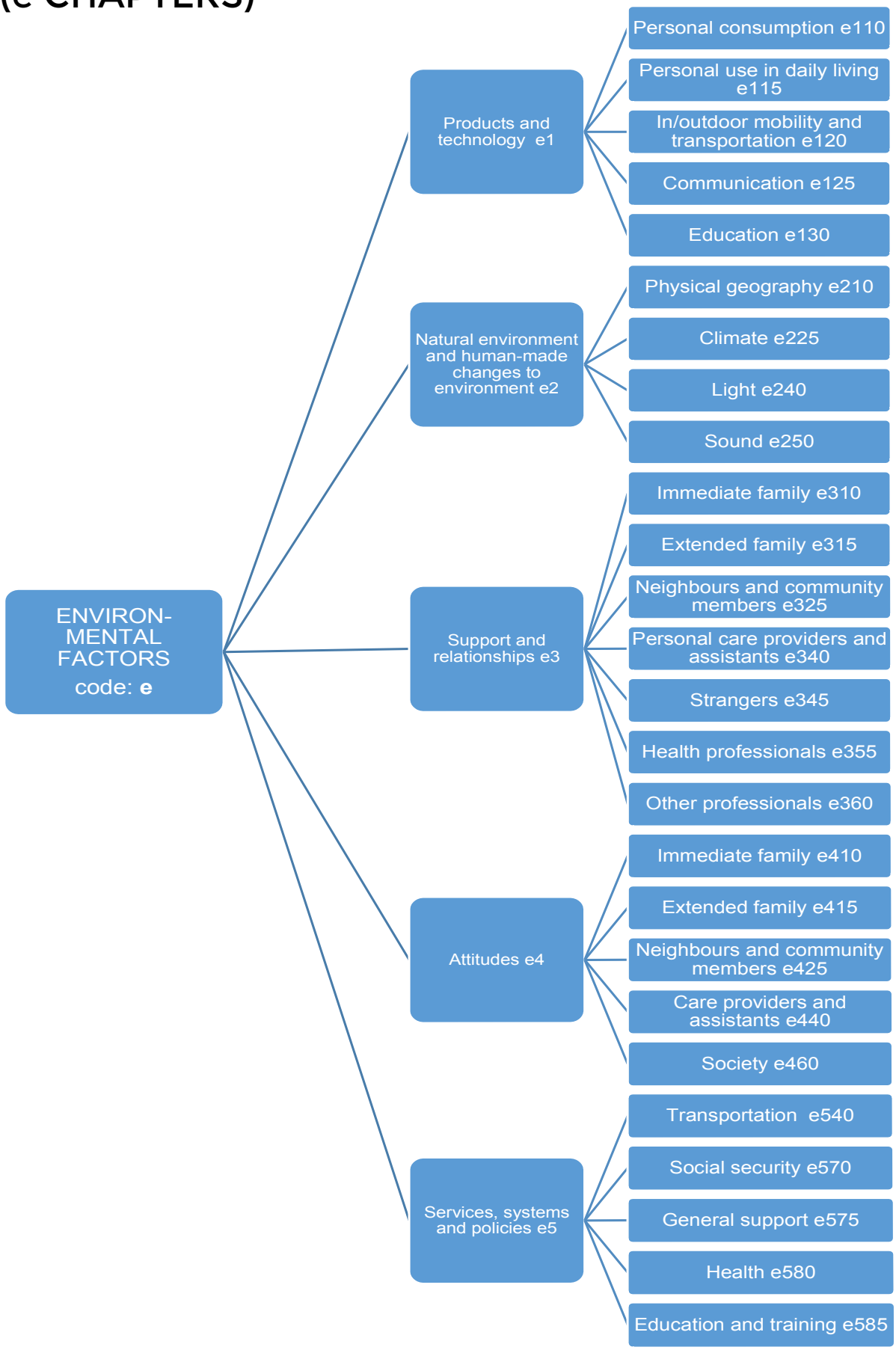
# APPENDIX 5: BODY STRUCTURES (s CHAPTERS)



# APPENDIX 6: ACTIVITIES AND PARTICIPATION (d CHAPTERS)

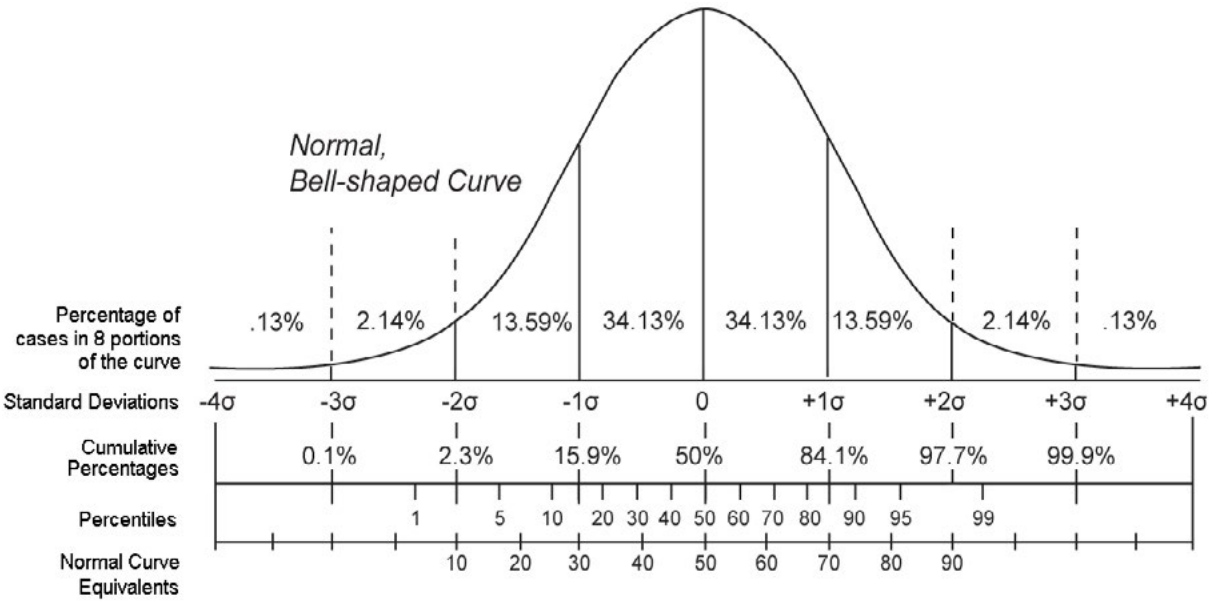


# APPENDIX 7: ENVIRONMENTAL FACTORS (e CHAPTERS)



# APPENDIX 8

## STATISTICAL NORMAL DISTRIBUTION




https://commons.wikimedia.org/wiki/File:PR_and_NCE.gif

# APPENDIX 9

## DISTRIBUTION OF EVERYDAY LIFE SITUATIONS (ELS)

According to the research of Adolfsson (2011: 74), these two age groups differ in terms of the categories of everyday life situations (ELS):

| d-CHAPTER DOMAIN AND CATEGORY | | AGE GROUP | |
|---|---|---|---|
| | | 0-6 years | 7-17 years |
| d3 Communication | | | |
| d399 | Communication | ✓ | |
| d4 Mobility | | | |
| d450-d469 | Walking and moving around | ✓ | ✓ |
| d5 Self-care | | | |
| d510-d530 | Hygiene | ✓ | ✓ |
| d450 | Dressing | ✓ | |
| d550-d560 | Eating and drinking | ✓ | ✓ |
| ? | Sleeping | ✓ | ✓ |
| d6 Domestic life | | | |
| d630-d649 | Household tasks | ✓ | ✓ |
| d7 Interpersonal interactions and relationships | | | |
| d760 | Family relationships | ✓ | |
| d8 Major life areas | | | |
| d820 | School education | | ✓ |
| d880 | Engagement in play | ✓ | ✓ |
| d9 Community, social and civic life | | | |
| d920 | Recreation and leisure | ✓ | ✓ |

# APPENDIX 10

## ICF-CY DEVELOPMENTAL CODE SETS

**INFANCY (00 TO 35 MONTHS)**

BODY FUNCTIONS

- Seeing functions (e.g., sense the presence of light; sense the form, size, shape and color of the visual stimuli)
- Hearing functions (e.g., sense the presence of sounds and discriminate the location, pitch, loudness and quality of sounds)
- Touch functions (sense qualities of bitterness, sweetness, sourness, and saltiness)
- Sensation of pain (e.g., the child reacts when falling, indicates pain in body part or generally)
- Emotions regulation and range of emotion (e.g. appropriateness of emotions like affect, sadness, happiness, fear, anger, frustration)
- Voice and producing sounds and speech (production and quality of voice, phonation, pitch, loudness)
- Heart functions (e.g., heart rate, heart rhythm, functions of heart valves, blood pressure, circulation)
- Respiration functions (e.g., respiration rate, respiratory rhythm, depth of respiration)
- Immune response (i.e., resistance to infections)
- Eating and drinking functions (e.g. chewing, sucking, biting, manipulation of food in the mouth, salivation, swallowing)
- Breakdown of food and tolerance to food (e.g., transport of food through stomach and intestines, breakdown of food, absorption of nutrients, functions of accepting suitable food and drink for digestion)
- Growth maintenance functions (attain expected physical milestones)
- Motor reflexes (i.e. involuntary contraction of muscles automatically induced by specific stimuli, infant reflexes)
- Muscle tone (i.e., tension present in resting muscles and the resistance offered when trying to move the muscles passively. It can appear like hypotonia, hypertonia, spasticity)
- Spontaneous movements. This is about the infant's movements and changes of body positions.
- Postural, balance or threatening reactions (supporting, self-protecting and defensive reactions)

ACTIVITIES AND PARTICIPATION

- Exploring objects by mouthing, touching, tasting or smelling
- Watching and Listening to engage in purposeful sensory experiences (i.e., intentionally experiencing auditory and visual stimuli)
- Learning through actions with objects (e.g., manipulate, bang, mouth or put a lid on a box)
- Learning through play and playing with objects, (e.g., stir with a spoon, pretend that a piece of wood is a car)
- Comprehending meaning of messages in spoken language, receiving and understanding verbal communication [Communication]
- Vocalizing when aware of another person in the proximal environment (e.g., babbling and producing other sounds in turn-taking activities)
- Changing basic body position (e.g. turn in bed, sit up, stand) [Mobility]
- Maintaining a body position (e.g., control head position, remain seated at school or stand in play)
- Using hands and arms (e.g., grasp and pick up objects, grasp raisins, button shirt, throw or catching a ball)

- Moving around (e.g., crawl, scoot, climb stairs, run and jump)
- Differentiation of familiar persons [Interpersonal Interactions and Relationships]
- Playing (e.g., engage with objects, toys, or others, occupy oneself in playful activity, alone or with another)
- Wakefulness, alertness, and awareness of the child or youth

ENVIRONMENTAL FACTORS

- Food and drink (e.g., appropriateness, nutrition, amount, consistency)
- Drugs (type of drug and amount for medical purposes)
- Products and technology used for play (e.g., household objects, toys, other products like balls, games, puzzles, or adapted material for play. Indoor and playground)
- Immediate family
- Health Professionals
- Individual attitudes of immediate family members
- Social support services, systems, policies (public assistance other than social security)
- Health services (e.g. access to early intervention, technical aids, other health services)

**EARLY CHILDHOOD (03 TO 05 YEARS)**
BODY FUNCTIONS

- Sleep functions (e.g., amount of sleeping and onset, maintenance and quality of sleep)
- Attention functions (e.g. sustain, shift, divide and share attention; concentration)
- Memory functions (e.g., to remember, learn and recall things)
- Perceptual functions (e.g., recognize and interpret sensory stimuli like auditory, visual, tactile, gustatory or olfactory stimuli)
- Sensation of pain (e.g. the child reacts when falling, indicates pain in body part or generally)
- Voice and producing sounds and speech (production and quality of voice, phonation, pitch, loudness)
- Heart functions (e.g., heart rate, heart rhythm, functions of heart valves, blood pressure, circulation)
- Immune response (i.e. resistance to infections)
- Respiration functions (e.g., respiration rate, respiratory rhythm, depth of respiration)
- Eating and drinking functions (e.g. chewing, sucking, biting, manipulation of food in the mouth, salivation, swallowing)
- Defecation (e.g., frequency, air or gases from the intestines, fecal consistency, voluntary control over elimination)
- Urination (e.g., frequency, urine retention, control over urination)
- Growth maintenance functions (attain expected physical milestones)
- Muscle tone (i.e. tension present in resting muscles and the resistance offered when trying to move the muscles passively. It can appear like hypotonia, hypertonia, spasticity)
- Postural, balance or threatening reactions (e.g., supporting, self-protecting and defensive reactions)
- Voluntary movement, (i.e. control and coordination). It can appear like clumsiness, dysdiadochokinesia

ACTIVITIES AND PARTICIPATION

- Learning through play and playing with objects, (e.g. stir with a spoon pretend that a piece of wood is a car)
- Developing competency using words, phrases or sentences to represent persons, objects, events etc
- Acquiring basic concepts like size, form, quantity, length, same, opposite

- Undertaking a single task or responding to a single communication (e.g., put on a sock, do homework, sort objects, play hide and seek, take instruction)
- Comprehending meaning of messages in spoken language, receiving and understanding verbal communication
- Comprehending meanings of nonverbal messages in body gestures, general signs and symbols, drawings and photographs
- Speaking and telling someone something (i.e., produce verbal communication)
- Using gestures, symbols and drawings to communicate (i.e., producing nonverbal messages)
- Having a conversation (i.e., initiate, maintain, shape or terminate communicative interactions)
- Using hands and arms (e.g., grasp and pick up objects, grasp raisins, button shirt, throw or catching a ball)
- Walking indoors or outdoors
- Moving around (e.g., crawl, scoot, climb stairs, run and jump)
- Moving around using equipment (e.g., use wheel chair, walker, or ski to move around)
- Toileting (i.e., regulating urination and defecation)
- Eating and drinking (i.e., indicate need for and coordinate tasks and actions of eating food and drinking)
- Interacting with people (i.e., basic interpersonal interactions including respond to other's feelings, show respect in relationships, use appropriate physical contact)
- Engaging in preschool education (e.g. acquire skills, follow teacher's instructions)
- Playing (e.g., engage with objects, toys, or others, occupy oneself in playful activity, alone or with another)

ENVIRONMENTAL FACTORS

- Food and drink (e.g., appropriateness, nutrition, amount, consistency)
- Drugs (type of drug and amount for medical purposes)
- Products and technology for personal use in daily living (e.g., furniture, stroller, chairs, personal care equipment, adapted or specially designed devices, and orthopedic devices)
- Products and technology for personal indoor and outdoor mobility and transportation (e.g., family car, cab. Bus, train, adapted chairs, walking devices, wheelchair, bicycle)
- Products and technology for communication (e.g., telephone, TV and video, computers/ email, glasses and aids for sight and hearing, aids for writing)
- Products and Technology for education (e.g., books, computers, educational toys, adapted material for learning such as computer software)
- Products and technology for culture, recreation, and sport (e.g., skis, musical instruments, adapted equipment)
- Products and technology used for play (e.g., household objects, toys, other products like balls, games, puzzles, or adapted materials for play; indoor and playground)
- Immediate family
- Extended family
- Friends
- Personal care providers and personal assistants
- Health professionals
- Individual attitudes of immediate family
- Individual attitudes of extended family
- Individual attitudes of health professionals
- Design, construction, and building products and technology of buildings for private use (e.g., thresholds, ramps, doorknobs, toilets, lighting, contrasts in color, kitchen interior).
- Social support services, systems, policies (public assistance other than social security)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