

Definition and Classification of Disability

Webinar 2 - Companion Technical Booklet



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With major thanks to Australian Aid for its strong support to UNICEF and its counterparts and partners, who are committed to realizing the rights of children and persons with disabilities. The Rights, Education and Protection partnership (REAP) is contributing to putting into action UNICEF's mandate to advocate for the protection of all children's rights and expand opportunities to reach their full potential.

Definition and Classification of Disability

Webinar Booklet

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What this booklet can do for you

The purpose of this booklet and the accompanying webinar is to assist UNICEF staff and our partners to get to know the **International Classification of Functioning, Disability and Health** (ICF) of the World Health Organization (WHO) and gain an understanding of how it fits within UNICEF's mission. The ICF is a standard and universal language and conceptual basis to understand and describe disability. It brings together the diverse models of disability and understands disability as a description of the situation of a person rather than as a characteristic of the person.

In this booklet you will be introduced to:

- *Why you should get involved with the ICF.*
- *Using the ICF to conceptualise disability.*
- *How the ICF relates to **inclusive education**.*
- *How the ICF can be used to support participation of all children.*

For more detailed guidance on programming for inclusive education, please review the following booklets included in this series:

1. Conceptualizing Inclusive Education and Contextualizing it within the UNICEF Mission
2. Definition and Classification of Disability (*this booklet*)
3. Legislation and Policies for Inclusive Education
4. Collecting Data on Child Disability
5. Mapping Children with Disabilities Out of School
6. EMIS and Children with Disabilities
7. Partnerships, Advocacy and Communication for Social Change
8. Financing of Inclusive Education
9. Inclusive Pre-School Programmes
10. Access to School and the Learning Environment I – Physical, Information and Communication
11. Access to School and the Learning Environment II – Universal Design for Learning
12. Teachers, Inclusive, Child-Centred Teaching and Pedagogy
13. Parents, Family and Community Participation in Inclusive Education
14. Planning, Monitoring and Evaluation

How to use this booklet

Throughout this document you will find boxes summarizing key points from each section, offering case studies and recommending additional readings. Keywords are highlighted in bold throughout the text and are included in a glossary at the end of the document.

If, at any time, you would like to go back to the beginning of this booklet, simply click on the sentence "Webinar 2 - Companion Technical Booklet" at the top of each page, and you will be directed to the Table of Contents.

To access the companion webinar, just scan the QR code.



Acronyms and Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
CRPD	Convention on the Rights of Persons with Disabilities
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
ICHI	International Classification of Health Interventions
UN	United Nations
UNICEF	United Nations Children's Fund
WHO	World Health Organization

I. What is Disability?

Key Points

- *Understanding environmental barriers to participation is a precondition to implementing inclusive education. Participation restrictions have to be part of the definition or classification of disability.*
- *Traditional disability categories reflect the **medical model** and highlight everything that a teacher cannot change. A new conceptualisation of disability is required to support inclusive education.*
- *The ICF developed by the World Health Organization goes beyond medical and social models and provides a more meaningful framework to understand disability.*

Disability in the Context of Human Rights

The human rights of children with disabilities have been reaffirmed in the **UN Convention on the Rights of Persons with Disabilities** (CRPD) since its adoption in 2006. The ratification of the CRPD means both the immediate obligation to ensure individual rights of all children with disabilities and the progressive realisation of their rights through systemic changes. This raises two questions: who are the children with disabilities, and therefore the holder of rights under the CRPD, and how is the impact of systemic changes on the lives of children with disabilities measured? Both questions are related to a more fundamental question: what is disability? The convention defines persons with disabilities as “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” (Article 1).

Activity

Anna, Sara and Pablo were all diagnosed with Down’s Syndrome. Pablo, born in 1974, is a well-known Spanish actor and a teacher. Anna, seven years old, spent the first three years in a Ukrainian orphanage before she was adopted by an American family. She attends her local school together with her friends. Sara is three months old and was born with fetal alcohol syndrome. She was abandoned at birth by her mother and her family does not want to look after her.

Consider the definition of the CRPD: Do Anna, Sara and Pablo have the same disability?

In Article 24 of the CRPD, inclusive education is seen as a tool to ensure the respect for human diversity and the full development of the talents, creativity and abilities of children with disabilities. It requires states to ensure reasonable accommodation and adequate support within the general education system. All signatory states need to take stock and are required to monitor progress towards full implementation of the convention. For this purpose, states are required to establish a framework to promote, protect and monitor the implementation of the convention. Inclusive education is a process of increasing learning and participation for all students. It is about gaining access, being involved and achieving meaningful outcomes. The term 'inclusive' highlights the necessity to give special attention to children who are vulnerable to exclusion and whose rights to education are often infringed upon. For more information on this topic, see Booklet 3 in this series.

Participation restrictions of children with disabilities have long been seen as direct consequences of disorders and impairments. Traditional disability terminology reflects this medical approach by 'zooming in' on individuals and neglecting environmental factors as contributors to disabilities. It focuses on medical causes and is blind to social dynamics, and in the context of human rights may be the most worrisome aspect: it reduces a person to one category, masking the complexity of the experience of disability. A traditional medical understanding of disability is overly focused on the individual, not sensitive to changes in levels of participation and unable to capture environmental influences. For more information on this topic, see Booklet 1 in this series.

Activity

A **human-rights-based approach** highlights the importance of enabling environments to ensure participation.

Think of enabling and disabling environmental factors that may have an impact on the lives of Anna, Sara and Pablo.

Children with disabilities are more often exposed to unsupportive environments, adding to their vulnerability and limiting their opportunities to learn and participate in meaningful ways. Such dynamics will have a disabling effect, thus aggravating the experience of disability. To break such vicious circles requires an understanding of disability which can map the interactions between characteristics of the person and the environment.

Clearly a new approach is needed to understand disabilities that goes beyond describing impairments. Inclusive education is about creating enabling environments and about empowering children to participate fully in society. In order to achieve this, disability has to be understood as something that describes life situations, not only people. Such a new conceptualisation needs to be sensitive, both to changes in the environment and to changes in participation. Universal Design for Learning is an important framework to develop flexible and adaptable learning environments.¹ But to fully implement Article 24, there is still a need to understand the impact of sensory, intellectual or physical impairments on learning and participation to implement effective individualised support measures.

The Problem with Traditional Disability Terminology

Traditional disability terminology understands disability as a problem belonging to a person. To describe this problem, a few characteristics are extracted, pulled together and labelled. The focus is on causes and characteristics, or in other words on the aetiology and pathology of diseases and disorders. For example, Down's Syndrome is a genetic disorder associated with a set of mental and physical symptoms that may range from mild to severe. But knowing that Anna, Sara and Pablo have Down's Syndrome does not tell us anything about their life situations, and knowing that all three have intellectual impairments does not help to understand their specific experiences of disability. Most importantly, knowing a person's disorder and associated impairments does not tell anything about their abilities and talents.

Categorical disability concepts reflect the medical approach to disability. Environmental factors are considered as determinants to explain the emergence of a problem or as risk factors that may aggravate a problem, but not as the problem itself. Complex social dynamics are reduced to terms like 'alcoholism', only to be considered as causes for impairments or disorders as in the case of Sara. Although the medical approach has been discredited as one-sided and unhelpful in the context of human rights, categorical approaches to describe disability still prevail. Most people don't question the premises that underpin these terms and the undue simplification of complex issues they represent.

Traditional disability terminology hides the dynamics and complexities a human-rights-based approach seeks to uncover. 'Learning disability', for example, refers to a participation problem defined against the expectations of teachers and schools. 'Mental retardation' implies delayed cognitive development and remains silent on a person's cognitive abilities. Attention Deficit Hyperactivity Disorder (ADHD) describes a limitation in carrying out specific activities, such as sitting on a chair for hours. Little thought is generally given to the fact that using such terminology automatically attributes the problem to the person. *Using labels attached to people for difficulties arising in situations undermines the efforts of inclusive education.*

One important argument against using traditional categorical disability terminology to describe the situation of children is that these *labels are blind to barriers in the environment*. Although diagnosed with the same disorder, three children with Down's Syndrome will most likely live in very different circumstances and therefore experience different challenges in their lives, some of them quite unrelated to their disorder but still contributing to their disability. Being born into a caring family or being institutionalised shortly after birth will make more of a difference to a child's development than having Down's Syndrome or not.

Inclusive education is about creating enabling environments.
Descriptions of disabilities, therefore, need to provide information on how this can be done.

Another argument against *categorical conceptualisations of disability* is that they highlight characteristics as *fixed and unchangeable*. It is understandable that such labels disempower teachers as they provide no lever for action within their expertise. Teachers need information on strengths and talents, but more importantly on children's actual learning experiences and participation. Three children with Down's Syndrome will be very different in terms of their capacity to interact with others, learn and adapt to specific classroom demands. Knowing about existing intellectual impairments does not help in understanding their abilities, talents and aspirations. The differences that really make a difference to learning remain hidden and are therefore often misunderstood.

Inclusive education is about ensuring learning and participation. Teachers, therefore, need to know how impairments affect participation and what can be done to minimise their impact.

It can thus be concluded that *traditional terminology in itself is a major barrier to the implementation of inclusive education*. It promotes prejudice and discrimination, and focuses on fixed characteristics rather than on what can be changed by teachers. It creates helplessness in teachers rather than informing their actions and makes them feel dependent on specialists to teach such children. Disability categories are blind to environmental influences, including the social processes that have led to the identification of a child belonging to that category.

Activity

Based on what has been said so far: Try to write down characteristic of a more adequate conceptualisation of disability.

A New Approach to Conceptualising Disability

The issues around labelling children as 'being disabled', and using a medical model to do so, were pointed out many decades ago. New approaches to defining disability have been searched for since the 1970s. Since then, many different perspectives to understand disability have been developed using a social model. But, in general, they focus more on the creation and dynamics of 'disability' as an abstract concept, rather than tackling the problem of actually describing the specific 'disabilities' that individuals experience. Disability has been set in the context of discrimination and poverty, and of diversity, denied access and

human rights. These perspectives imply that *disability is a more complex phenomenon than simple categories suggest* and that disability is better understood as the result of an interaction between characteristics of the environment and the person.

The CRPD links disability to persons as holders of rights, but focuses on the interaction of impairments with barriers in the environment that hinder full and effective participation in society. *Essentially, it is the situation of the person that should be highlighted, not the person.* This understanding of disability should not only guide the monitoring and implementation process, it should also guide all disability-related activities of UNICEF as a member of the UN development group.

It is another UN special agency, the World Health Organization, that has – amongst others – the mandate to develop and publish a series of health-related classifications. One member of the family of international classifications is the *International Classification of Functioning, Disability and Health*, published in 2001. A derived version of the ICF for Children and Youth (ICF-CY) was published in 2007. In 2012, WHO decided to merge the two classifications back into one while completing other updates and revisions.

The ICF has been declared as the new standard classification for disability by the World Health Assembly. It should be used in the future to understand disability, plan intervention and monitor progress towards fulfilling states' duties in promoting the rights of persons with disabilities.

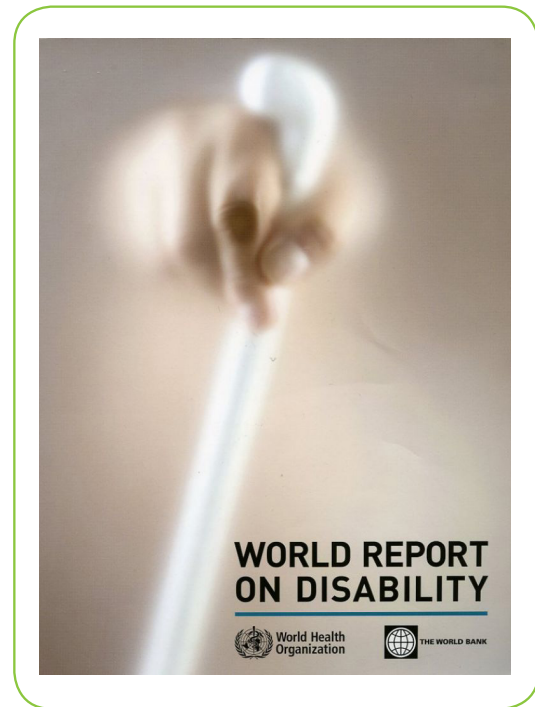


Figure 1: The World Report on Disability uses the ICF as a conceptual basis

Disability is understood as a multidimensional phenomenon, with disability and functioning marking the ends of a continuum of human functioning that becomes visible in the involvement in life situations. It is the result of complex interactions between the person and the environment.

Different life situations involve people in essential human activities, such as learning, communicating, interacting or moving around. How fully people with disabilities can participate in these life domains is dependent on many factors. These life domains are reflected in the different articles of the CRPD (e.g. living independently, personal mobility, education or work and employment). Getting to know and use the ICF is therefore central for the implementation and monitoring of the convention.

II. Getting to Know the ICF and the ICF-CY

Key Points

- *The ICF is one of three classifications related to health and well-being, encompassing all aspects of human health and health-relevant components of well-being.*
- *The ICF as a framework provides a language to describe disability in the context of environmental facilitators and barriers. The ICF describes situations of people, not people themselves.*
- *Functioning and Disability are umbrella terms to describe the result of the interaction between all components of the ICF. The ICF model visualises the current understanding of this interaction. The ICF can be used in all sectors and for all age groups, but it should be used in ways that are empowering to people with disabilities.*

Philosophy and Background Information

The ICF is one of three components of the ‘WHO Family of International Classifications’. The International Classification of Diseases (ICD) focuses on health problems such as diseases, disorders and injuries. It was first published in 1901 and is currently under revision, also to improve its compatibility with the ICF. The diagnostic approach taken in the ICD has been pre-dominant ever since, leading to the categorical approach to create distinct categories to distinguish different types of disabilities.

The roots of the ICF go back to the 1970s, when the need was felt to capture the consequences of diseases on the lives of people rather than merely diagnosing the diseases themselves. A draft classification, called International Classification of Impairments, Disabilities and Handicaps (ICIDH), was published in 1980 for field-trial purposes. It took over 20 years before a revised version was finally endorsed by the World Health Assembly, in 2001. The third member of the family is currently under development and will focus on health interventions (International Classification of Health Interventions, ICHI).

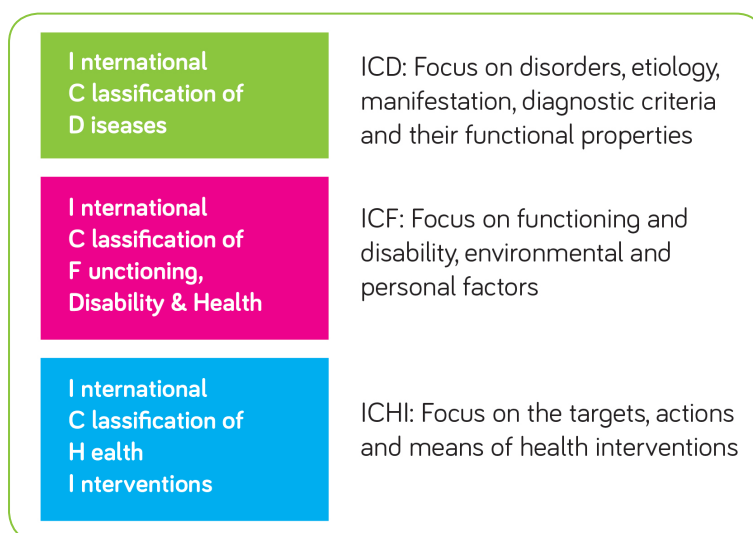


Figure 2: The WHO Family of International Classifications (WHO-FIC)

The fact that WHO has developed three different classifications makes the case that disorder, disability and intervention need to be considered separately.

Anna, Sara and Pablo share the same ICD-Code. Think of differences in functioning (also considering environmental factors) and differences in the support they may need to participate fully.

Today, disability is no longer conceptualised as a consequence of a disease, but is understood as a dynamic interaction between a person's health condition, environmental factors and personal factors (no longer a linear, but interactive model).

The World Health Organization's constitution from 1948 includes the definition of health as "*a complete state of physical, mental and social well-being, and not merely the absence of disease or infirmity*". Health is the result of a dynamic interaction between biological, psychological and social processes. In the same tradition, the ICF is based on a **bio-psycho-social** model. The universe of the ICF encompasses all aspects of human health and health-relevant components of well-being, including for example having meaningful relationships and enjoying high-quality education. It does not cover circumstances where discrimination or exclusion is brought on solely by social factors, e.g. due to religion, gender or ethnic background. Nevertheless, within the context of health and well-being, it has universal application.

The ICF is not only about people with disabilities, it is about all people.

The strength of the ICF is to map the components of health as a basis for understanding the dynamics between health problems, functioning and disability and contextual factors. Functioning and disability are understood as the result of complex interactions between biological, psychological and social factors. The ICF offers a common language to study the dynamics of these components and their consequences and therefore a basis to understand levers to improve the life situation of people experiencing disabilities.

The ICF provides definitions for the components of functioning and disability, but *it does NOT prescribe or dictate who is 'normal' and who is 'disabled'*. International data on disability clearly shows that disability is perceived and defined differently in different contexts. Identification rates differ as does the percentage of people describing themselves as having a disability. This may be due to differences in life experience, differences in awareness or the use of different thresholds to identify functional limitations as a problem.

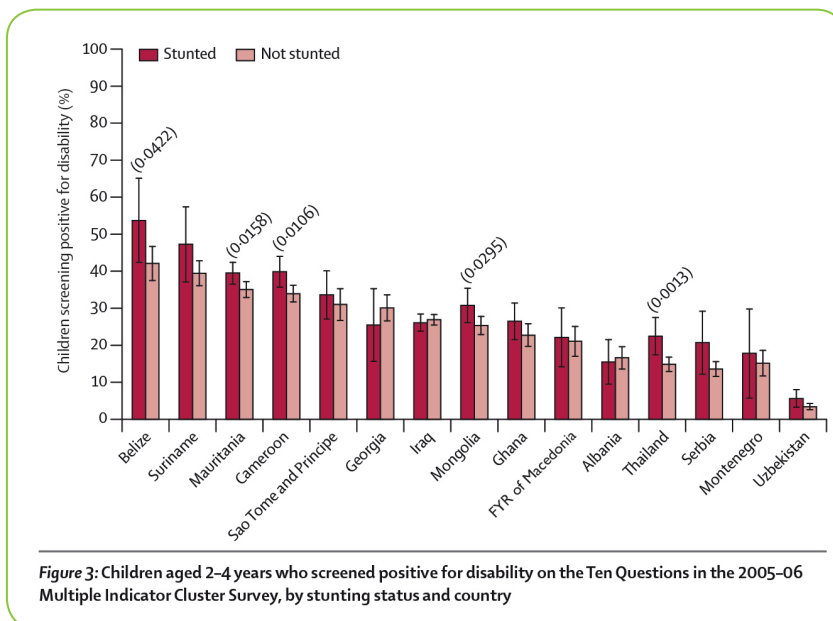


Figure 3: Children aged 2-4 years who screened positive for disability on the Ten Questions in the 2005-06 Multiple Indicator Cluster Survey, by stunting status and country

Figure 3: Results from the MICS 2005-06 show differences in reported disability across countries (Gottlieb et al. 2009)

Pablo Pineda was seven years old when he was diagnosed with Down's Syndrome, having learnt to read at age four. Today he works as a well-known actor and as a teacher. Should he be 'counted' as having a disability?

The definition of thresholds and therefore the decision as to who should be included or excluded from being identified as having a disability depends on the specific purpose. For example, if the purpose of identification is to provide cash benefits or support services, only a few people will be identified as eligible. The criteria applied may consider the severity of their impairments or restrictiveness of their life circumstances. Sara would certainly be seen as having a disability under these criteria. But when it comes to anti-discrimination legislation the definition should be broad, because although Pablo experiences hardly any restrictions in functioning, he may still be discriminated against on the basis of having Down's Syndrome. By implementing universal design in public spaces, anyone limited in their mobility will benefit: not only people with disabilities, but also mothers with prams, people with luggage and senior citizens.

Activity

Think of Anna, Sara and Pablo. Under which criteria might they be identified? And for which purposes (e.g. service provision, social protection, assertion of their rights) might they be identified?

UNICEF and WHO published a joint discussion paper on Early Childhood Development and Disability in 2012. It introduces the ICF and the ICF-CY as a common framework for the two agencies to be used in their efforts to implement children's rights.

Organization of the ICF

The ICF organises its universe in two main parts. The first part deals with Functioning and Disability while the second part covers Contextual Factors. Each part has two components: (1) Functioning and Disability – the Body Functions and Body Structures component and the Activities and Participation component; and (2) Contextual Factors – the Environmental Factors and the Personal Factors. The primary focus of the classification is on functioning and disability, as health and health-related components of well-being. The contextual factors represent the external (environmental) and internal (personal) factors that influence functioning in specific life situations.

The Functioning and Disability component of the ICF is organised around body systems (body functions and body structures), such as 'mental functions'/structures of the nervous system' or 'functions of the digestive, metabolic and endocrine systems'/structures related to the digestive, metabolic or endocrine systems', and around areas of life (activities and participation) called 'domains', such as 'learning and applying knowledge', 'communication', 'mobility' or 'interpersonal interactions and relationships'. But *as a classification it does not define how 'disability' should be described or how disabilities develop; it simply provides the different constructs and domains that can be used for this purpose.*

The ICF is like a language: it provides the terminology to talk about disabilities – but which story is told and why will depend on the user.

The following model was developed to visualise the current understanding of the interaction between the various components:

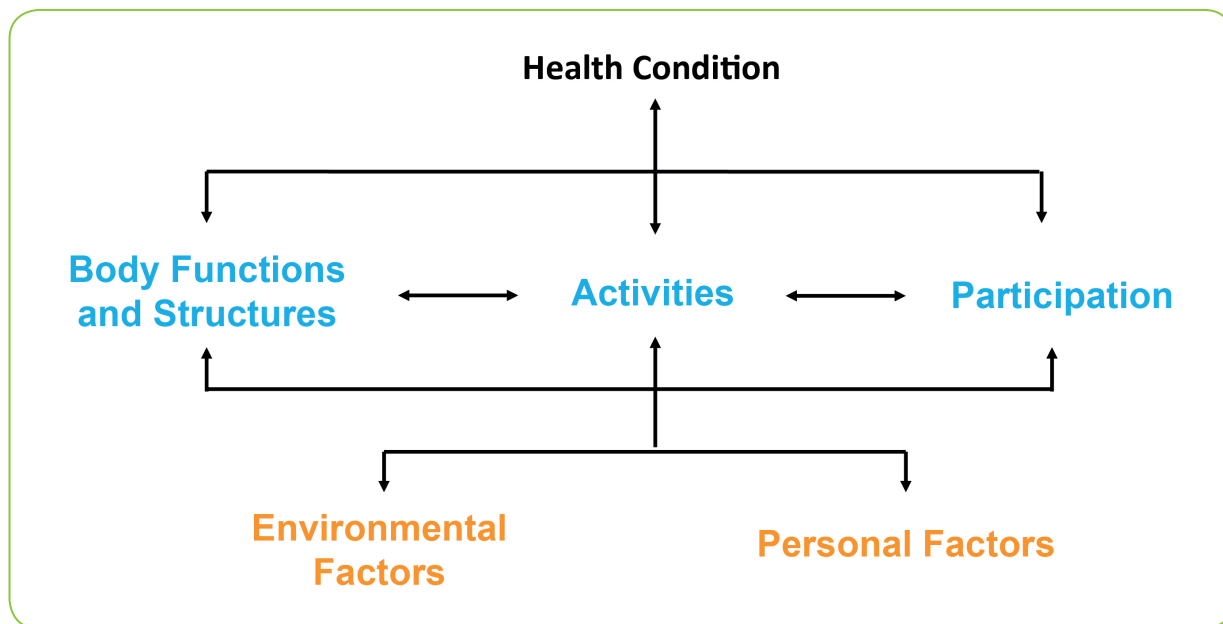


Figure 4: ICF-Model

A person's functioning in any domain is the result of complex interactions with a health condition (classified with the ICD), other domains of functioning and disability, as well as environmental and personal factors. If the full health experience is to be described, all components should be used, not merely the body functions and structures. Personal factors are part of the model, but not part of the classification because of the large social and cultural variance associated with them.

Each component consists of various domains represented as chapters. Within each domain or chapter there are categories which are the units of classification. To use the ICF not only as a common language but as a classification therefore implies the selection and use of individual categories or codes. Any category relevant to describe health or health-related states can be selected and together with a qualifier used to describe the extent or magnitude of functioning or disability in that category. Categories can also be chosen to emphasise an advantageous aspect of functioning, not only to highlight problems. The extent of a problem in a specific category can be expressed with numeric codes, from 0 (no problem) to 4 (complete problem), which are added to the alphanumeric category code.

Definitions: In the context of health

- **Body functions** are the physiological functions of body systems (including psychological functions).
- **Body structures** are anatomical parts of the body such as organs, limbs and their components.
- **Impairments** are problems in body function and body structure such as a significant deviation or loss.
- **Activity** is the execution of a task or action by an individual.
- **Participation** is involvement in a life situation.
- **Activity limitations** are difficulties an individual may have in executing activities.
- **Participation restrictions** are problems an individual may experience in involvement in life situations.
- **Environmental factors** make up the physical, social and attitudinal environment in which people live and conduct their lives.

Activity

Think of Anna, Sara and Pablo. What are the likely differences between them considering body functions and structures, activities and participation as well as environmental factors?

Try to list three characteristics for each person.

Describing Functioning with the ICF

The ICF can be used at different levels of detail to describe functioning and disability. At the broadest level, the components, concepts and terms of the ICF together with the model provide a basic language to talk about and reflect on the nature and dynamics of functioning and disability in the context of environmental barriers or facilitators. This is useful to share different observations and develop a broad common understanding of a person's life situation. It can also be useful to make different perceptions or opinions visible, e.g. related to the origin and dynamics of an observable problem: *are problems with learning in school caused by an underlying problem at the body level (e.g. higher cognitive functions), or by a lack of*

support by the teacher (environmental factor)? There is no need to use the individual ICF categories or codes for this purpose.

If the ICF is used as a classification, the individual categories are used to code information. Coding with the ICF requires not only an in-depth understanding of the classification, but also the use of adequate sources of information and assessment tools. It is well beyond the scope of this booklet to provide the necessary knowledge and expertise to use the ICF as a classification.

There is no universal approach to measure functioning and, in many instances, there may be different ways used by professionals of different backgrounds. For example, *problems in 'seeing functions' require a specific diagnostic procedure carried out by a specialist. But problems in 'reading' may be identified on the basis of teacher observation, a performance test or self-evaluation.* In some situations it may be more relevant to do the coding based on self-reported data, for example when trying to map participation in family relationships or community life. For other purposes, for example establishing eligibility for disability benefits, more objective approaches to document problems in functioning will be more adequate.

Activity

WHO has set up a browser version of the ICF and ICF-CY. It is useful to learn about the ICF and has a search function to see, for example, which codes are related to 'Learning' or to 'Food'.

<http://apps.who.int/classifications/icfbrowser/>

Go to the Browser and look for the characteristics that you have written down related to Anna, Sara and Pablo.

One of the challenges of describing functioning by using the ICF is how to choose the relevant codes from the over 1,450 codes included in the classification. The ICF-CY has even some additional codes to better describe functioning in very young children. Which information is perceived as relevant may also differ as a function of the assessor's perspective and training. Essentially, the data source, the approach taken to obtain information and the level of detail documented has to be *fit-for-purpose*. If the purpose is to understand current difficulties related to participation in classroom activities, then different contents or categories will be selected than if the purpose is to train for specific communication skills. For example, different domains of functioning are more relevant to judge cognitive abilities than to describe social participation. *The advantage of the ICF is that it allows component-specific or problem-centred selections of content while still providing a unifying framework in which all this information can be placed.*

Another advantage of the ICF is the fact that *functioning and disability is understood as a continuum*. For each category, not only the absence or presence of a problem can be documented, but also the *extent of the problem*. The ICF qualifiers can be used for this purpose. Especially when describing participation restrictions, the views of teachers, parents and children may differ. By referring to the qualifiers, the level of functioning perceived by different people or observed in different settings is made visible. This is important as it will influence the choice of intervention or support strategy.

The language and content of the ICF can also be used to capture the understanding behind constructs such as 'lack of intelligence', 'behavioural problems' or 'discrimination' when used by different people to describe the situation of one child. Rather than debating whose perception of the problem is right or wrong, the knowledge behind these constructs can be arranged in the ICF to highlight similarities and differences in understanding underlying problems, as well as complementary or contradictory information.

Application of the ICF

The ICF is an information system to organise data related to functioning and disability. As such it can be used in any setting or for any purpose. The ICF was developed in the spirit of partnership and seeks to promote the rights of persons with disabilities. WHO confirms the right of people to be called what they choose and supports a participatory approach in defining 'disability'. It is therefore important that people are empowered by classification and assessment and not disempowered or discriminated against. Like every scientific tool, the ICF can be misused or abused. WHO has therefore set out ethical guidelines for the use of the ICF with regard to respect and confidentiality, clinical use of ICF and the use of ICF information in a broader social context.

The framework of the *ICF places the situation of people in the centre of attention rather than people themselves*. With this focus it supports a shift away from a charity model to a rights-based model of advocacy for social change. In line with the CRPD, the ICF and the ICF-CY have a broad scope which includes the impact of the environment on participation and social inclusion of children with disabilities. It can highlight discrimination and environmental barriers by describing the situation of persons with disabilities within broader human-rights issues such as exclusion in education systems or employment. Therefore, it is well positioned to be used for advocacy at the local, regional, national and international levels. Using the ICF as a common language can also help build bridges between disability activists, the broader public, policy-makers and professionals to develop national strategies to promote the rights of persons with disabilities.

All life domains are relevant to promote the rights of persons with disabilities. Education, health and social sectors, therefore, have to co-ordinate their work and policy development accordingly. The ICF can provide a common language to develop cross-sectoral strategies

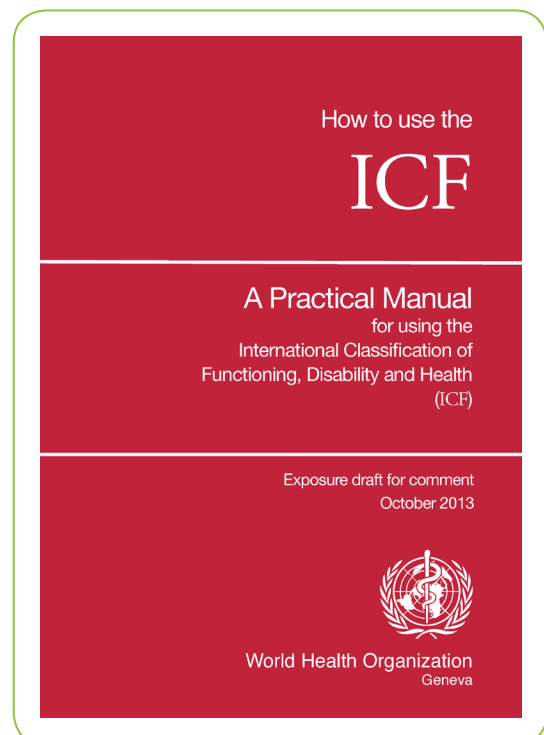


Figure 5: The ICF Practical Manual helps with the application of the ICF

or action plans. Countries can use the ICF in their national legislations and policies in order to fulfil their obligations, having signed and ratified the CRPD. The inclusive perspective on disability the ICF takes is useful to highlight areas where people with disabilities encounter participation restrictions. This could help to raise awareness and mobilise necessary social action.

The Republic of Moldova has developed a Road for the Introduction of the ICF as part of the Action Plan of the Government of the Republic of Moldova's Strategy on the Social Inclusion of Persons with Disabilities. UNICEF Moldova is involved in providing technical support with regards to the situation of children with disabilities.

Population-based surveys and censuses are important to gain a 'helicopter view' of the situation of adults and children with disabilities. The Washington Group on Disability Statistics is mandated by the United Nations to develop a set of disability measures based on the framework of the ICF. A short set of six questions can be used in censuses to identify populations with functional limitations that have the potential to limit independent participation in society. In collaboration with UNICEF it has developed an extended set of questions on child disability, including environmental factors. Comparing the life situation and levels of participation in education and family life of those with, compared to those without, disability is an important measure for social inclusion. For further information on this issue, see Booklet 4 of this series.

The ICF can also be used as a framework and classification to guide identification and assessment of service needs, as well as for planning and evaluation of interventions or service provision. It should also be implemented in the training of health professionals, teachers and others who work together with people with disabilities.

WHO is currently developing an Implementation Database for the Family of International Classifications (WHOFIC). The section on the implementation of the ICF will contain information about which country is using the ICF and in which way.

<http://apps.who.int/gho/data/node.whofic>, go to 'Implementation of WHO Classifications'

Notes

III. Defining Disability for Inclusive Education

Key Points

- *Defining disability is an active act of categorisation – something people do to make sense of things. How individuals think influences how they act, so there may be a need for re-thinking.*
- *Participation and participation restrictions are the starting point to understanding disability in the context of inclusive education. Identifying participation gaps is important to understanding discrimination and lack of support.*
- *Inclusive education is about creating enabling environments, not only in schools but in all life domains that are important for learning and participation. It is therefore important to identify environmental barriers beyond the classroom.*

Thinking about Disability

To develop a new understanding of disability, there is a need to challenge the knowledge behind traditional conceptions of disability.

Classification is the process of assigning entities to mutually exclusive classes in accordance with an established set of principles. In the case of the ICF, the parts and components provide a structure and the model clarifies the relationship between them. The ICF categories are the building blocks to describe disability and they remain explicit and visible during the categorisation process (unlike categorical conceptualisations, where the category masks these building blocks). Applying the codes to other people requires in-depth knowledge of the ICF, but applying them to one's own knowledge can help develop a deeper understanding of what disability is in people's minds.

Pablo Pineda once said in an interview: "Down's Syndrome is not a disease, but another personal characteristics". Translated into the ICF, he is saying that Down's Syndrome should be considered a personal factor, not a health condition. Homosexuality was removed from the ICD only for its 10th revision, in 1990, as health professionals acknowledged that homosexuality does not pose an inherent obstacle to health and well-being. Human knowledge is fluid and evolving. Premises held dear today may be outdated tomorrow. Before judging others' views, one should seek to better understand one's own thinking.

The ICF can also be understood as an information system in which the 'thinking' behind disability categories can be made visible. It can be used to de-construct disability constructs. This can be helpful to develop a totally new understanding of what disability is, or rather how it can be defined.

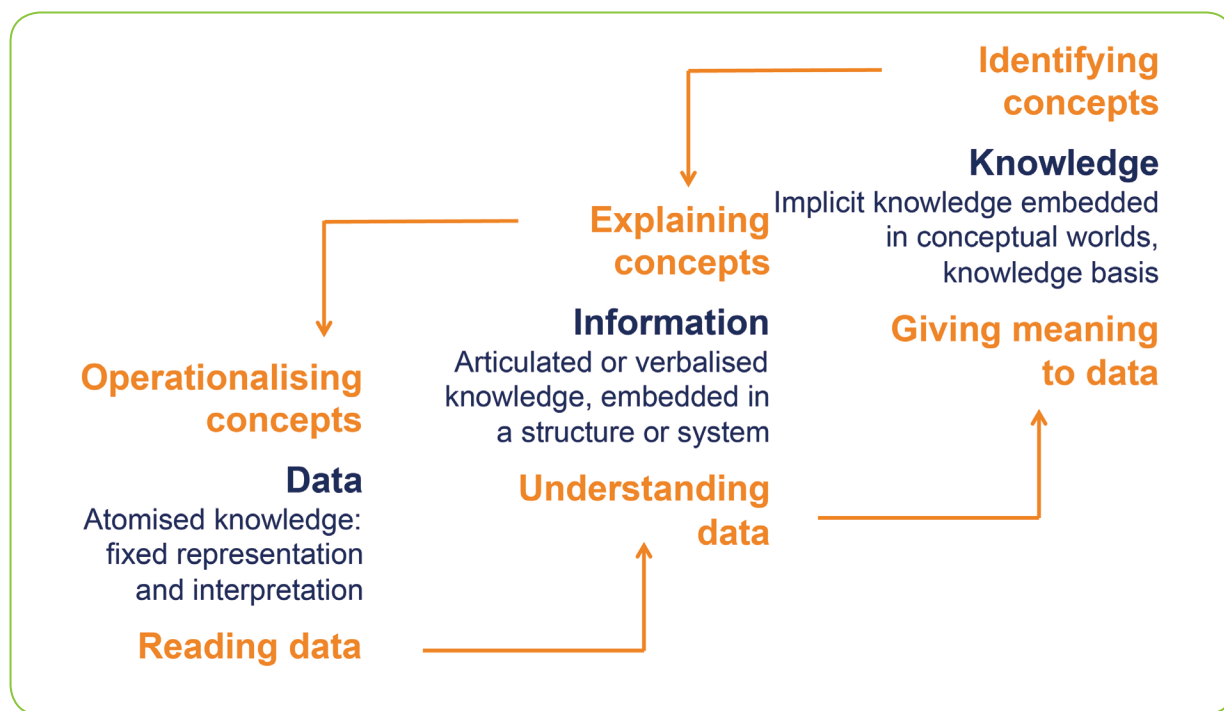


Figure 6: ICF as an information system to link data to knowledge

To develop a new definition of disability, the usage of the present categories needs to be understood. Differentiating between data, information and knowledge can help here. *Knowledge* is imbedded in our way of thinking – specific thought traditions that differ from one profession to the other. The ICF can be used to explain concepts and make differences in understanding visible. Reversing this process, all available *information* organised in the framework of the ICF is a good basis for gaining an understanding of the dynamics behind the experience of disability. Again, different people may have different views here and the ICF classification and model can help make them visible.

On the other hand, the ICF can be helpful in organising and understanding *data* gained from observation, tests or interviews. Using the ICF opens up the debate as to which component of functioning and disability should be assessed using which method: where is it more valuable to have self-reported data and the observation of a clinician? and which aspects of functioning can be assessed by a teacher? Clearly, there is no simple and clear answer to these questions, but they are useful to gain a better understanding of how to best think and understand disability.

Focus on Participation

When defining disability in the context of inclusive education, participation should be the starting point of analysis and intervention. *Promoting participation means minimising the impact of existing impairments on activities through changes in the environment.* Inclusive education is about ensuring that all children learn to their fullest potential. It is about creating opportunities and enabling environments in schools and other educational settings. Participation in education is a goal in its own right, but it is also a means to an end: education is the most powerful enabler of social inclusion and well-being of adolescents and adults with disabilities. Ensuring participation today is about creating a foundation upon which future participation is built. Therefore, participation in education is also about achievements and accomplishments, and about having something to take away at the end of schooling.

Participation is about what children and youth do, how they do it, where they do it and what they do it for. Participation is about being involved in typical settings (e.g. regular school), with typical routines (e.g. learning with others, eating in the canteen) that lead to meaningful outcomes (e.g. transition to higher education, gaining employment). Being involved means carrying out activities (competence component), with a sense of belonging or communion (emotional component) and autonomy or agency (cognitive component). All three aspects of participation need to be considered, not only one of them.

When participation restrictions are analysed in the context of health, the ICF can be used to better understand the situation of a child or youth. Participation in the ICF is defined as 'involvement in life situations' and participation restrictions are problems experienced by an individual in getting involved, being involved or remaining involved. The ICF provides the domains and categories in which participation can be assessed.

Domains of Activities and Participation in the ICF and ICF-CY:

- Learning and applying knowledge.
- General tasks and demands.
- Communication.
- Mobility.
- Self-care.
- Domestic life.
- Interpersonal interactions and relationships.
- Major life areas (Education, Work and Employment, Economic Life).
- Community, social and civic life.

But the ICF does not prescribe the method to collect data that can inform the level and quality of participation. Which data source is most adequate for which domain or category can be debated and what is perceived as 'gold standard' depends on the purpose of the assessment, but also on factors such as age of the child, professional background of the assessors and their attitude toward disability. The views of the child and family must always be considered.

Activity

In getting to know the ICF and ICF-CY you have listed different characteristics for Anna, Sara and Pablo. Check the domains listed above and check it against your list.

How can you use all domains to get a better understanding of their abilities and talents?

Disability is a social construct. The social construction of children with disabilities may in itself be a barrier to participation. They are often defined as being or having a problem, thereby focusing on what they cannot do rather than on what they can do.

Impairments are often viewed as something that prevents children from participating. By viewing children with disabilities as suffering, dependent, passive and vulnerable, 'protection' can become a barrier to participation. The ICF can help to highlight such constructions when professionals and parents explain the dynamics of participation restrictions.

Participation of children with disabilities is generally measured against the participation of other children. To identify participation gaps between children with and those without disabilities is an important first step to overcome barriers of inclusion. But when assessing participation gaps, it is important to reflect on one's own understanding of 'ideal participation' based on a mainstream agenda. There may be a need to accept diversity of approaches to participate and make use of learning opportunities.

Focus on Environment

Education is all about creating enabling environments and opportunities to learn. To have a clear understanding of environmental facilitators and barriers is therefore most important. The ICF provides a list of environmental factors from which relevant content can be drawn to describe different situations where barriers impact on the overall participation in education. Such barriers may not only be found in the immediate school settings, but also at home or on the way to school. Inadequate food and clothing, unavailability of assistive devices, long distances between school and home, school fees and other factors may prevent the family from sending a child to school.

Environmental Factors in the ICF and ICF-CY:

- Products and technology.
- Natural environment and human-made changes to environment.
- Support and relationships.
- Attitudes.
- Services, systems and policies.

Institutional care creates environments where all domains of life are formally administered, a constant control exerted, activities constrained and behaviour manipulated to ease the functioning of the institution. Such environments make it almost impossible to be involved and to develop a sense of participation. To develop a sense of competence, autonomy and belonging is only possible in environments that are adaptable to the needs of the child and through personalised interactions that help develop a sense of self. Where children with disabilities cannot grow up in their own families, alternative social environments should be created that help children to participate in all life domains.

When analysing environmental factors, it is useful to start with one life domain and consider what is needed to ensure participation. For example, select 'communication' and try to identify environmental factors that have an impact on the level and quality of communication across different life situations (e.g. interacting with parents at home, relating to friends and peers, participating in classroom). With this focus, general barriers that impact on communication across different life situations can be identified and broad strategies developed to overcome these participation restrictions.

Activity

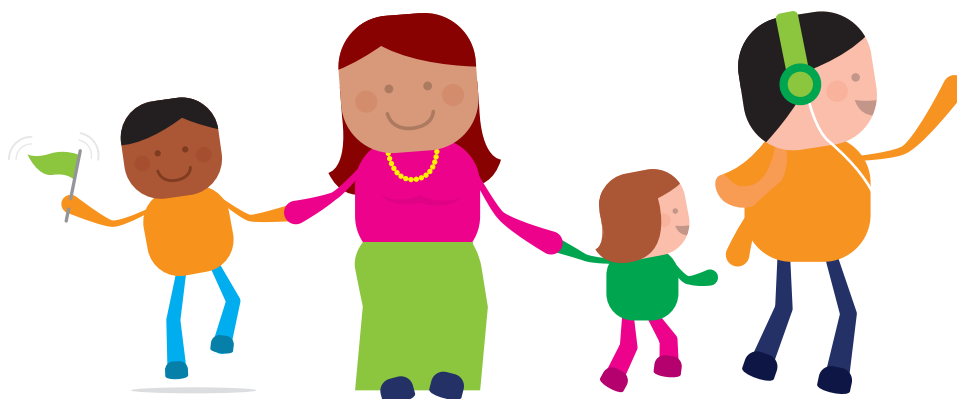
In getting to know the ICF and ICF-CY you have listed different characteristics for Anna, Sara and Pablo. Have you made any reference to enabling or disabling environments?

Include factors that likely will have an impact on their lives!

Once the cross-cutting barriers and facilitators have been identified, the different life situations should be considered – for example, the child’s life situation in school. Participation is defined as being involved in typical settings and typical routines. School settings and routines (sequences of activities) generally imply certain expectations related to abilities, but also self-regulation, motivation and volition. Unless special attention is given to ensure participation for all children, school settings and routines generally don’t lend themselves to alternative approaches or adaptations. Universal Design for Learning can help eliminate barriers related to instructional goals, methods, materials and assessment.

A third approach to identifying barriers to education is not to focus on overall school settings and routines, but on specific situations created by teachers. Each of these situations implies the usage of certain tools or strategies and often teachers are not aware of the assumptions embedded in the situations they create. In other words: teachers have certain expectations related to what children can do and how they should do it. Children unable to carry out these activities as envisaged by the teacher will be unable to participate. A situational analysis will be needed to identify mismatches between teachers’ expectations and students’ ability to participate.

Notes



IV. Using the ICF in Inclusive Education

Key Points

- *Identification is important, but bears the risk of discrimination. In the context of inclusive education this process should always include the identification of barriers in the environment.*
- *Performance and behaviour are the result of complex interactions, not a proxy for characteristics of the child. Understanding this interaction is the starting point for planning for learning.*
- *Goals should be envisaged as future participation; the means to reach the goals are essentially changes to the environment.*
- *Planning for inclusion is about creating social spaces in which children are able to benefit from support in order to learn and participate.*

Identification

Early identification is important to create enabling environments and provide support to ensure participation. But identification also always bears the risk of discrimination. Teachers, for example, tend to expect less of children identified as having a disability and, as a consequence, do not provide similar challenging learning opportunities as to other children. In some countries identification gives access to cash benefits, but not to services. Consequently, the specific requirements to ensure education are not addressed.

The notion that the right specialist is able – once and for all – to diagnose a child, to identify underlying causes and to prescribe a treatment is a powerful idea. The impact of a disorder on functioning is better understood today and it is largely dependent on what else happens in the life of a child. If a child is enabled to participate fully in all life domains, the impact of the underlying health problem can be minimised. Disabilities can arise at any point in life when environmental factors impact negatively on health. Therefore, identification cannot be a once-in-a-lifetime event, but should be planned as an on-going process with a focus on enabling identification.

Disability, as understood by the ICF, is the result of a complex interaction between functioning and contextual factors. Consequently, identification should take environmental factors into account and not only rely on diagnosing disorders and impairments. Participation restrictions are depended on the child's life situation and cannot be measured in clinical settings. Identification should also consider information provided by parents, teachers or other informants. If the notion that disability is not something pre-defined, but rather is a social construction, is taken seriously, identifying disability should be seen as a process of co-construction. Using the ICF model as a map to identify relevant information and organise it into a common framework allows different understandings to be highlighted.

In 2011, Switzerland introduced an ICF-based eligibility procedure which takes environmental factors into account. The procedure identifies children with disabilities to ensure their rights and requires a statement on developmental and learning outcomes.

What disability is and how it is best identified remains debated and will always depend on the experiences, expertise and intentions of everyone involved in the process. Respecting individuals' rights means respecting and acknowledging their views. The ICF and ICF-CY can help to bring different views together in one framework:

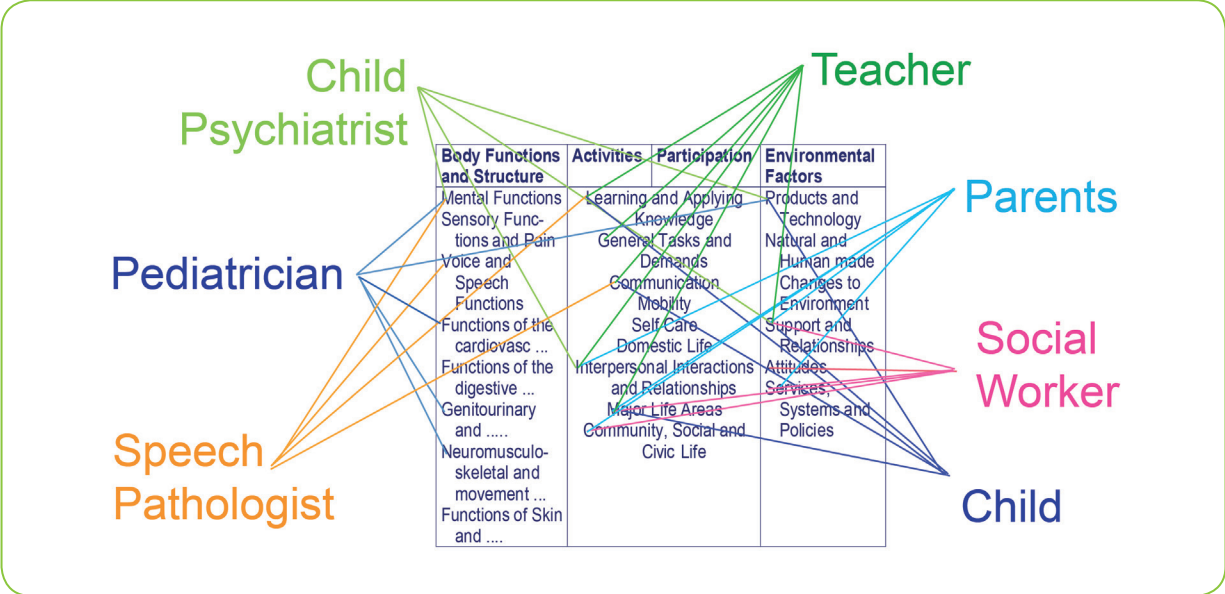


Figure 7: Using the ICF to bring together different views and information

Identification, therefore, should be understood as an on-going process rather than an event that happens once in the life of a child. Even establishing eligibility – if it is to be linked to services rather than result in labelling – needs to be a recurring procedure. *Multiple data sources should be used by a multi-disciplinary team with expertise related to the different components of the ICF.* The process of identification should include the identification of participation gaps as well as strategies to address these. This would also bring the identification process in line with the requirements of the CRPD.

The module on child functioning and disability developed by UNICEF and the Washington Group is a set of questions on functioning to identify the sub-population of children that are at greater risk than other children of the same age of experiencing limited social participation. The questions are based on the ICF and ICF-CY.

See: <http://data.unicef.org/child-disability/overview> (go to Notes on the Data)

Assessment for Learning

The ICF organises human functioning in a multi-dimensional classification taking a situational approach by responding to the question: what is the current life situation of a child? Assessment for learning envisages future life situations and focuses on information important to facilitate learning and development towards this goal. *Assessment for learning focuses on the abilities of a child and looks into the future.* The problem set out to solve is not one of fixing impairments but of supporting children to develop and learn to their fullest potential. But although participation is the main focus of assessment for learning, it is still important to understand the impact of impairments on learning and participation. A bio-psycho-social approach helps to not lose sight of problems that need to be addressed to facilitate learning. At the same time it allows a clear focus on present participation as a basis to plan for future participation.

While education is nothing else than a complex arrangement of situations, its quality is essentially reflected in child-related outcomes. Educational concepts, therefore, generally focus on the child rather than situations, and on processes of acquisition rather than dynamics of interactions between teacher and student. Most teachers don't take a situational approach to understand participation restrictions; they attribute them to the child. 'Performance' is understood as a proxy for characteristics such as intelligence, achievement motivation and talent, not as the result of a complex interaction between student and teacher characteristics as well as other environmental factors. *When teachers formally or informally assess children's problems, they still follow a child-centred rather than situational approach.* They identify student characteristics, such as being shy, introverted or aggressive, without considering the situations in which these characteristics were observed. The ICF invites teachers to de-construct concepts like 'ADHD' and 'behaviour disorder' and to contextualise them within the situations created by them. This opens a window on environmental factors contributing to the participation restrictions, and therefore on strategies to create enabling environments.

The strength of the ICF is that it can represent information related to functioning and disability and therefore *allows the equal exploration of problems and potentials.* Problems are traditionally synthesised into a label by applying differential diagnostic criteria. In other words, some functional properties of the child are selected and linked to a problem. Potentials can be understood as future competencies or abilities. Here, quite different functional properties of the child are selected and linked to participation. The ICF can help 'cross-walk' between these two very different perspectives to make sure that the impact of an underlying health problem is neither over- or under-estimated when assessing for learning

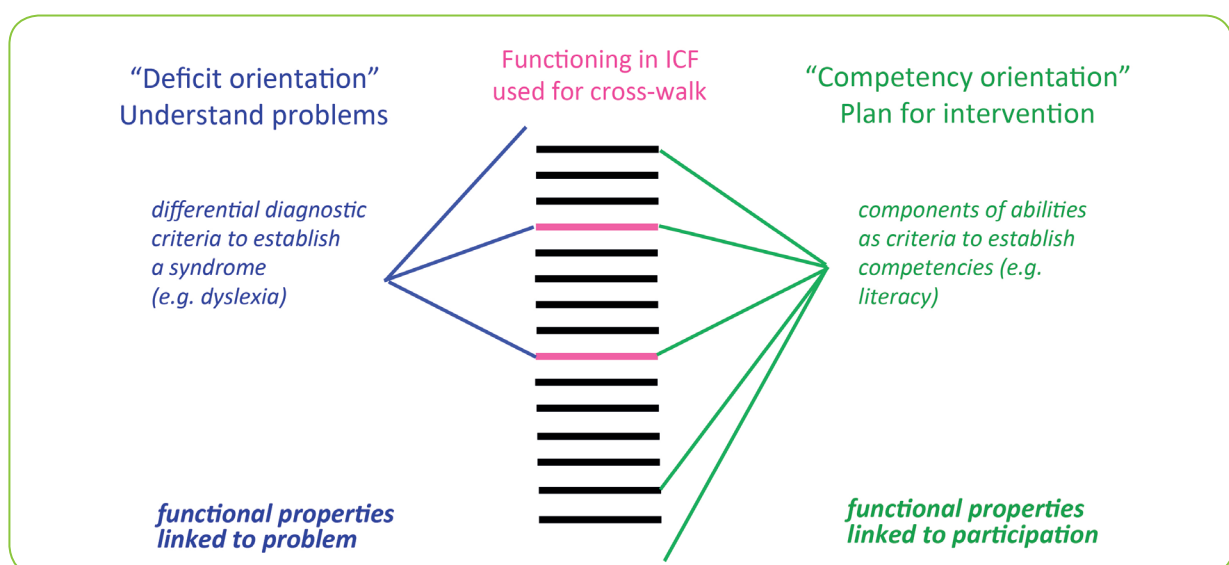


Figure 8: Using the ICF to link problem-based and resource-based views

Assessment for learning requires an adequate understanding of present participation and a vision of future understanding as a basis for the development of strategies to support the necessary learning processes to get there². It is therefore more than simply assessing participation and participation restrictions. Assessment for learning also implies a sense-making process that involves cross-walks between problem-based and competency-based thinking and reasoning. Once a reasonable understanding is achieved of the current situation, an estimation or prognosis of expected changes and future achievements is needed.

Key questions to ask while assessing for learning focusing on participation and environment:

- Where am I going? (Expected changes and future achievements)
- Where am I now? (Current participation in current environment)
- How do I close the gap? (Overcoming barriers and addressing contradictions)

The ICF framework and model can be used to make these thoughts explicit. Teachers' thinking about disability, their understanding of the dynamics of disability and their expectations of children with disabilities can be a barrier to inclusion. Tools that facilitate collaborative problem-solving and visualise these thought processes can support the development of a professional approach assessment for learning.

Planning and Evaluating Teaching and Interventions

Assessment for learning is the necessary first step towards planning for learning. Because the ICF is oriented towards the present, the ICF model needs to be expanded to provide a framework for educational planning. Educational interventions should always focus on future participation as envisaged in educational goals or in the contents of education.

In Armenia a step-to-step approach was used for analysing existing tools and concepts, learning about the ICF and developing tools for assessment and planning purposes in schools based on the new philosophy and classification of the ICF.

Each country has its own approach to curriculum design. In countries where the curriculum is represented as contents that need to be taught, it will be more difficult to develop links to student participation. Many countries are in the process of moving from a content-based curriculum to a competency-based curriculum, therefore describing what young people should be able to do upon completing their education. The shift from input-based to an outcome-based approach makes planning for learning easier. In the ICF the outcomes of education can be linked to the achieved participation level in the different life domains.

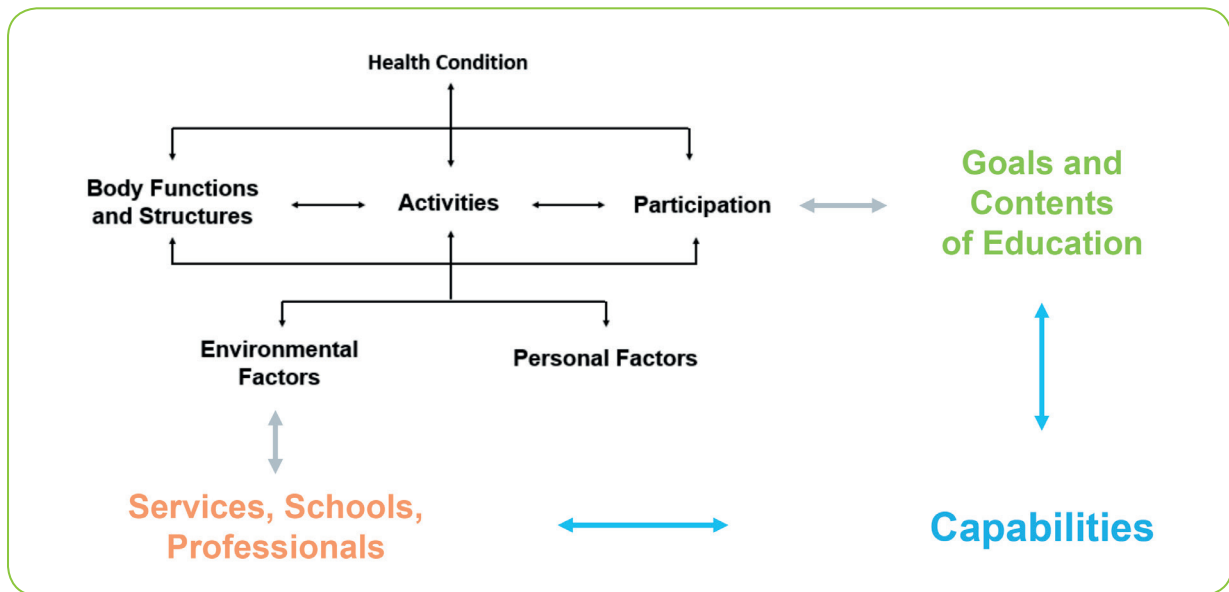


Figure 9: Expanded ICF-model to include planning information

Planning does not only imply goal-setting: it also implies envisaging actions. From the perspective of the child in question, these actions are reflected in changes to the environment. Following the medical model, teachers and other professionals have the tendency to primarily think about providing a different environment for learning, for example special interventions, rather than thinking about changes in the current environment. The five chapters of environmental factors can help to consider these changes and help teachers understand that they themselves are part of that environment, and that the most effective change may be changing their attitudes or ways of teaching.

When thinking about changes to the environment, the ICF can help in taking a situational approach. Not all environmental factors necessarily have either a positive or negative impact on all life situations. For example, a personal assistant can be a facilitator to participating in learning situations, but may be a barrier to developing peer relationships. Considering all life domains of the ICF and anticipating the overall impact of planned interventions can help avoid creating new barriers in other areas of participation. This will also help to coordinate different actions across settings and professionals. Planning for inclusion is about creating social spaces in which children are able to benefit from support to learn. The Russian developmental psychologist Vygotsky's zone of proximal development provides a useful framework to envisage support as something oriented towards participation.³

Key planning questions focusing on participation and environment:

- What? What should be learnt next? (Objectives)
- Why? Why should it be learnt? (Purpose, Values)
- Who? Who should be involved? (Commitment)
- How? How should it be learnt? (Tools, Strategies)
- Where? Where should it be learnt? (Enabling Environments)
- When? When should it be learnt? (Planning coordinated actions)

V. Summary

The International Classification of Functioning, Disability and Health is a member of the World Health Organization's Family of International Classifications (WHO-FIC), a set of international classifications on health which provides a framework that governments, providers and consumers can use as a common language. The ICF is a classification of health and health-related domains and can be used to describe functioning and disability of an individual and of populations in a context. The ICF includes a list of environmental factors to describe facilitators and barriers that a person may experience. A version for children and youth (ICF-CY) was developed in 2007.

Since its publication in 2001, the ICF has been recognised as the new standard to conceptualise disability. It is the reference framework and classification to monitor the implementation of the Convention on the Rights of Persons with Disabilities. Disability is understood as an umbrella term to encompass impairments, activity limitations and participation restrictions. The ICF uses neutral language and is based on a bio-psycho-social approach to understand disability. The ICF model represents the current understanding of the interaction between a health condition, functioning and disability and contextual factors.

The ICF provides a useful framework to understand disability in the context of inclusive education. Because it takes a universal approach, it does not pre-include or pre-exclude any child or adult from having or developing disabilities. The ICF provides the building blocks for a definition of disability, but does not define disability. Different definitions can be derived for different purposes. For a prevention programme in early childhood a broader definition of disability will be used than for establishing eligibility to receive cash benefits.

The ICF invites users to think about their own understanding of disability and how this influences their perception of a person, and the approach to solving identified problems, including their beliefs and attitudes. For inclusive education, the concept of participation is most important; here, the ICF provides a framework and common language to explore the dynamics resulting in participation restrictions. Inclusive education is about environments and how changes to the environment can help children participate to their fullest potential. The ICF helps to bring together information from different sources to reach a fuller understanding of current barriers to participation.

The ICF provides a common framework and classification which can be used to create tools and procedures compatible with the human-rights-based approach and the philosophy of inclusive education. Adequate tools need to be developed for identification, assessment, planning and evaluation purposes. Some countries have already developed such tools and there is an increasing body of experience that can be shared between countries and educational settings.

Notes

Glossary of Terms

Bio-Psycho-Social Approach to Disability used by the International Classification of Functioning, Disability and Health brings together medical and social models of disability. This approach provides a coherent view of different perspectives of disability from a biological, individual and social perspective.

Convention on the Rights of Persons with Disabilities and its Optional Protocol (A/RES/61/106) was adopted on 13 December 2006 at the United Nations Headquarters in New York, and was opened for signature on 30 March 2007. There were 82 signatories to the Convention, 44 signatories to the Optional Protocol, and one ratification of the Convention. This is the highest number of signatories in history to a UN Convention on its opening day. It is the first comprehensive human-rights treaty of the 21st century and is the first human-rights convention to be open for signature by regional integration organizations. The Convention entered into force on 3 May 2008.⁴ For more information visit: <http://www.un.org/disabilities/>.

Human-Rights-Based Approach is a conceptual framework for the process of human development that is normatively based on international human-rights standards and operationally directed to promoting and protecting human rights. It seeks to analyse inequalities which lie at the heart of development problems and redress discriminatory practices and unjust distributions of power that impede development progress.⁵

International Classification of Functioning, Disability and Health conceptualizes a person's level of functioning as a dynamic interaction between her or his health conditions, environmental factors and personal factors.⁶ It defines functioning and disability as multidimensional concepts relating to: the body functions and structures of people, the activities people do and the life areas in which they participate, and the factors in their environment that affect these experiences.

Inclusion is where there is recognition of a need to transform the cultures, policies and practices in school to accommodate the differing needs of individual students, and an obligation to remove the barriers that impede that possibility.

Inclusive Education is “a process of addressing and responding to the diversity of needs of all learners through increasing participation in learning, cultures and communities, and reducing exclusion within and from education. It involves changes and modifications in content, approaches, structures and strategies, with a common vision which covers all children of the appropriate age range and a conviction that it is the responsibility of the state to educate all children.”⁷

Medical Model of Disability explains disability as a health problem or medical condition of an individual that can be treated or made to go away with medical assistance. Therefore, disability is the result of the medical condition. The individual with a disability is seen as being in need of a cure, and it is the health professional's responsibility to alleviate her or his pain and suffering. *[This is **not** the model UNICEF currently follows.]*

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