International Journal of Neurologic Physical Therapy
2016; 2(1): 5-11
Published online January 21, 2016 (http://www.sciencepublishinggroup.com/j/ijnpt)
doi: 10.11648/j.ijnpt.20160201.12

Review Article

Use of the International Classification of Functioning, Disability and Health – Children and Youth (ICF-CY) in the Management of Children with Disabilities

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To cite this article:
Margaret M. Mweshi. Use of the International Classification of Functioning, Disability and Health – Children and Youth (ICF-CY) in the Management of Children with Disabilities. *International Journal of Neurologic Physical Therapy.* Vol. 2, No. 1, 2016, pp. 5-11.
doi: 10.11648/j.ijnpt.20160201.12

Abstract: The International Classification of Functioning, Disability and Health-Children & Youths version (ICF-CY) is a universal and multi-dimensional conceptual framework to health, human functioning, and disability with detail to cover functioning in childhood and youth. Since the ICF-CY provides a framework and a structure for collecting and organizing information, it may influence assessment, intervention planning, and the preparation of outcome evaluation. Using the ICF-CY framework could enhance holistic management for children with disabilities and may also guide researchers and clinicians in their selection of an outcome measure for use in a study and/or clinical practice although standard approaches to the evaluation of activities and participation, and environmental facilitators and barriers are required. However, the psychometric adequacy of the ICF-CY has been doubted due to the low reliability and validity hence may not be used in totality as a measuring instrument, but as a screening tool that classifies. The ICF-CY framework clearly has demonstrated the focus of current management practices, as well as strengths and weaknesses in actual practices of childhood rehabilitation.

Keyword: ICF-CY, Conceptual Framework, Classifications, Disabilities

1. Introduction

The ICF-CY is a new paradigm of disablement in which disability is viewed as the product of person - environment interaction and provides a multidimensional framework and taxonomy of four components of the body functions and structures, activities/participation, and environmental factors [1]. It is a derived version that expands the coverage of the International Classification of Functioning, Disability and Health (ICF) that was developed by the World Health Organization [2] as an international classification system with focus on health and functioning in daily life, rather than on medical diagnosis [3]. The ICF-CY offers a new way to conceptualize and document characteristics of children's function and their environments [2]. The ICF and ICF-CY are both universal in the sense that they can be used to describe functioning of all people, not only persons with disabilities [4, 5, 6].

2. The Development of the ICF-CY

The development of the ICF-CY model was guided by relevant research and theory. It is a version that expands the coverage of the ICF with specific content and additional detail to cover functioning in childhood and youth [7, 1]. Although it has exactly the same structure as ICF, some items have been added to the components of Body Function, Body Structure, Activity/Participation, and Environment [5, 8]. Additionally, some modifications to items intended to meet the need for the assessment of children and youth have equally been made. More than 200 changes have been made with the most significant being in the Activity/Participation dimension [8, 9, 10, 11, 12, 13].

3. The Current Paradigm of Disablement

The ICF-CY is a current paradigm of disablement in which

disability is viewed as the product of person–environment interaction and provides a multidimensional framework and taxonomy of four components of body functions and structures, activities/participation, and environmental factors [1]. The ICF-CY allows more developmental aspects of functioning to be coded, but focuses more on learning and child-specific factors, like engaging in play and learning to write are very important [1, 14, 15, 16, 17]. Although it provides a common language, it focuses on the relation between health status and changes that emerge in development from infancy to adolescence.

4. Applications of the ICF-CY

The applications of ICF-CY in health, education and child services involve clinical applications in the use of universal language for: *the assessment of child functioning, profiling individual differences, clarifying diagnoses and co-morbidity, framing intervention & documenting outcomes* [1, 18, 19]. Since the ICF-CY provides a framework and a structure for collecting and organizing information, it may influence assessment and intervention planning [20, 21, 22, 23]. For instance, many physiotherapists working with children with Cerebral Palsy (CP) incorporate the ICF-CY into practice as it focuses on health rather than the consequences of disease or disability. The components of body function and body structure, activity and participation interact dynamically with each other and with personal and environmental factors. Using the ICF-CY framework clearly has demonstrated the focus of current management practices, as well as strengths and weaknesses in actual practices for these children. Using the ICF-CY framework could enhance holistic management for children with CP [24]. Further, a systematic content analysis of outcome measures used in studies with children with CP was done and the review found great diversity in the ICF-CY contents of the outcome measures that were used in this population which indicates the complexity of CP. The review provides information about content of measures that may guide researchers and clinicians in their selection of an outcome measure for use in a study and/or clinical practice with children with CP [25]. Another systematic review on paediatric arterial ischaemic stroke (AIS) population was done on outcome studies focussing on functioning or disability using the ICF-CY framework and results revealed that standard approaches to the evaluation of activities and participation, and environmental facilitators and barriers are required [26].

However, the intended use of ICF-CY is as a conceptual framework and a common language for the purpose of recording problems during childhood that involves functioning in environmental contexts. The main focus of the ICF-CY as a classification is to document children's participation in everyday life. It can also aid clinicians working with children in need of specific support to enable their participation in everyday life activities [27]. Functioning is influenced by individual contextual factors and not on medical diagnosis alone [1]. Each individual exhibits some degree of functioning in each domain described by the classification [28]. Knowing how a disease affects functioning enables better planning of services, treatment and rehabilitation for persons with long-term disabilities or chronic conditions. Ultimately, the ICF-CY can be used as a conceptual model and also for classifications although some researchers have made no distinction between it being a model and its classifications.

5. The Conceptual Model and Classification of the ICF-CY

5.1. ICF-CY as a Conceptual Model

There is a great need to distinguish between the ICF-CY as a model and as a classification system [29]. Notably, the ICF-CY presents an interactive conceptual model in an attempt to integrate the individual and social model of disability into the bio-psychosocial model [30, 2]. The background of bio-psychosocial model is from body functioning which is denoted by *bio*, participation in a life situation by *psycho* and the *social,* a link between the two and describes how the individual performs activities [29]. The model was derived from both a traditional *'medical model'* of human functioning focusing on the consequences in everyday life of having body impairment, and a *'social model'* focusing on how society constructs difficulties in participation [29]. The two models were linked by bringing in activity as a unifying construct.

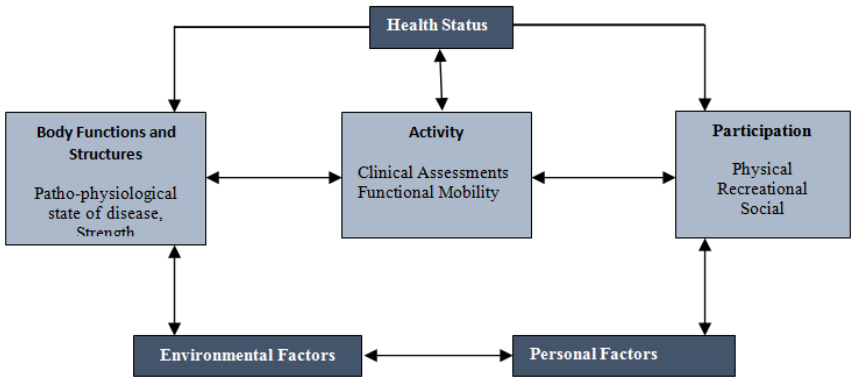

Figure 1. *International Classification of Functioning, Disability and Health-Children and Youth Version (WHO, 2007).*

The ICF-CY model shows an intricate relationship between six dimensions: health conditions being; bodily factors, i. e. body functions and structures; activities, such as abilities to perform actions; participation, such as the experience of being part of society; and contextual factors, i. e. environmental and personal factors (*figure 1*). The model has a conceptual framework of the ICF. Some extra information has been added to three of the main aspects of functioning being: *patho-physiological state of disease and strength* to the domain on body, *clinical assessments and mobility* to activity and *physical, recreational and social* to participation. It has been noted that activity is a prerequisite both for identifying the consequences of body impairments on everyday functioning, and for identifying everyday activities in which people with difficulties in functioning cannot participate. The three aspects of functioning in ICF-CY, i. e. body, activity and participation are also related to hindering and facilitating aspects of the environment.

The ICF-CY model can be seen as a conceptual model that has the potential to be applied on numerous ecological levels and to be used as a basis for generating assessment instruments on all levels [29]. It has been conceptualized that the classifications of the ICF-CY do not aim to model the process of disability but aim to provide building blocks for researchers who wish to create theories of disability [2, 31]. However, the ICF-CY qualifies to be a valid conceptual model that can be applied in early childhood intervention and habilitation services, because: (a) *it covers the content considered important to assess and intervene with pediatric services and* (b) *has a structure that allows for aggregating information from individuals up to societal level.*

5.2. ICF-CY as a Classification

The ICF-CY classification has received a lot of attention starting from the original version in 2007, to what is being encouraged for use currently. For instance Cieza and Stucks [32] adapted the original ICF-CY classification and this was further adapted by Simeonsson and colleagues [15] and lately the adjustments made by Klang [33] to producing the classification in the recommended current state. The classification of the ICF-CY is organized into two parts that contain components (*figure 2*). The first part presents Functioning which comprise of components of *Body functions, Body structures and Activities and Participation.* Functioning is presented as an umbrella term for *Body functions* and *Structures* and *Activities* and *Participation.* Disability is considered an umbrella term for impairments in Body function, Activity limitation and Participation restriction. The second part presents Contextual factors that comprise of *Environmental factors* and *Personal factors*, although the personal factors are not classified in the ICF-CY [33]. The availability of these classifications has contributed to significant interest in their promise as a common language for health and social services as well as education [15, 17, 34, 35].

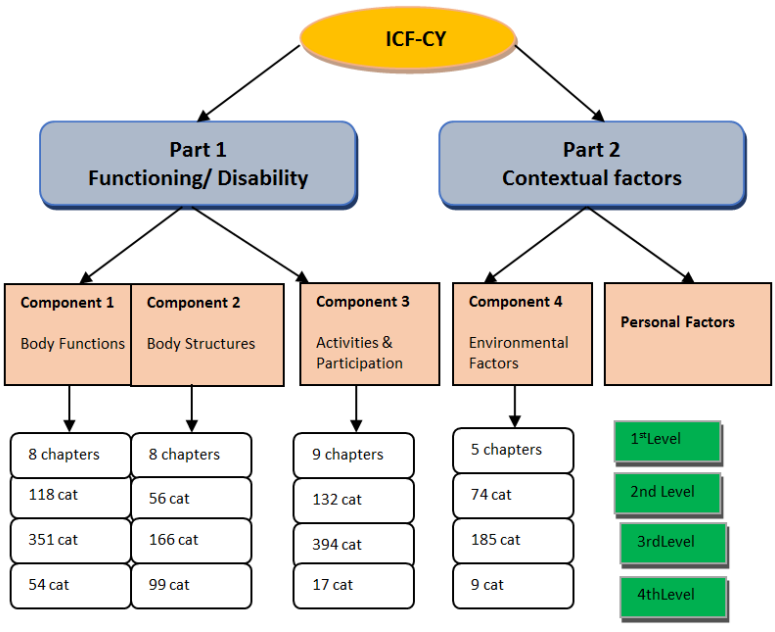

Figure 2. *Structure of the ICF-CY as a classification (Adolfsson, 2011).*

Adolfsson [4] presents the ICF-CY classification of codes that includes four components, while the model is presented with two parallel components. The components arise from two parts being part one presenting: *functioning disability* while part two presents the *contextual factors*. Part one has *three components* being body function, body structure and the third combining activity and participation. Part two presents the *two components* of environmental and personal factors. Below the extensions of the four components are the chapters and categories of the ICF-CY. The author labored to classify the two major parts and the four components, but some limitations still exist.

The first part comprises functioning disability but the distinction between "*disability*" and "*functioning*" is not easily made. The relationship between functioning and disability is quite abstract. Since functioning and disability are fundamental ingredients of health, therefore calling the first part as "*Health Status*" would help clarify the confusions that have been created by the lack of figurative presentation of the three variables in the ICF-CY model. Functioning is used as a positive or neutral word and the negative aspect is called disability, therefore, the author of this paper attempts to clarify the missing components by presenting body structures and body functioning into individual components as presented by [4] but separating participation from activity and eventually illustrating the classification in *figure 3*. This is actually in line with the ICF/ICF-CY model that defined the construct of disability as an umbrella term covering three aspects: impairments, activity limitations, and participation restrictions affected by barriers in the environment, reflecting that understanding disability as an individual problem is insufficient [2, 31]. Pediatric rehabilitation aims to augment a child's abilities to participate in everyday meaningful activities in the *child's home, school*, and *community environments*. Whether by *improving performance, adapting activities, modifying environments, educating* and *supporting families, or preventing disability*, ultimately therapists strive to optimize children's functions. It is therefore recommended that future studies separate activity from participation in the checklist of the ICF-CY. This is also shared by Adolfsson [2] who stated that additional work is needed to create reliable and valid instruments that make it possible to discriminate between activity and participation and also by Maxwell (2012) who has observed that the theoretical representation of participation in the current ICF/ICF-CY model does not make the frequency-intensity distinction that would have to be carefully considered and this is unlikely to create a satisfactorily useful tool. It must be noted that chapters and categories of the components have not been included in *figure 3*, but some inclusions on the environmental and personal factors have been made. It is recommended that personal factors be quantified and expanded more for the component to be helpful in screening.

Uniform coding conventions are an important prerequisite for maintaining high data quality (Dahl, 2002). The ICF-CY has categories considered units of the classification arranged in a stem-branch-leaf scheme in which lower-level categories share attributes of higher-level category (Klang, 2012). The alphanumeric system is used in which letters and numbers denote different levels in the hierarchy of the classification. Letters *b, s, d,* and *e* are used for the components *Body functions, Body structures, Activities and Participation* and *Environmental factors.* The letters are followed by a numeric code to denote chapter number (1st level), followed by the codes on the second, third and fourth levels (WHO, 2007). Following a series of substantial works on improving the checklist of the ICF-CY, a relatively recent study done by Ellingsen (2011) clustered items into the following age ranges: 0-2 years, 3-5 years, 6-12 years and 13-17 years. For instance, the ICF-CY 3-5 years category includes some items, e. g. "sensation of pain" (b280); "defecation functions" (b525); "urination function" (b620) under body function. Some other items are "learning through play & actions on objects" (d131)"; walking indoors or outdoors" (d450) and "eating" (d550) under activities and participation while the items on "immediate family" (e310); "individual attitudes of health professionals" (e450), "general social support services, systems and policies" (e575) are under environmental factors.

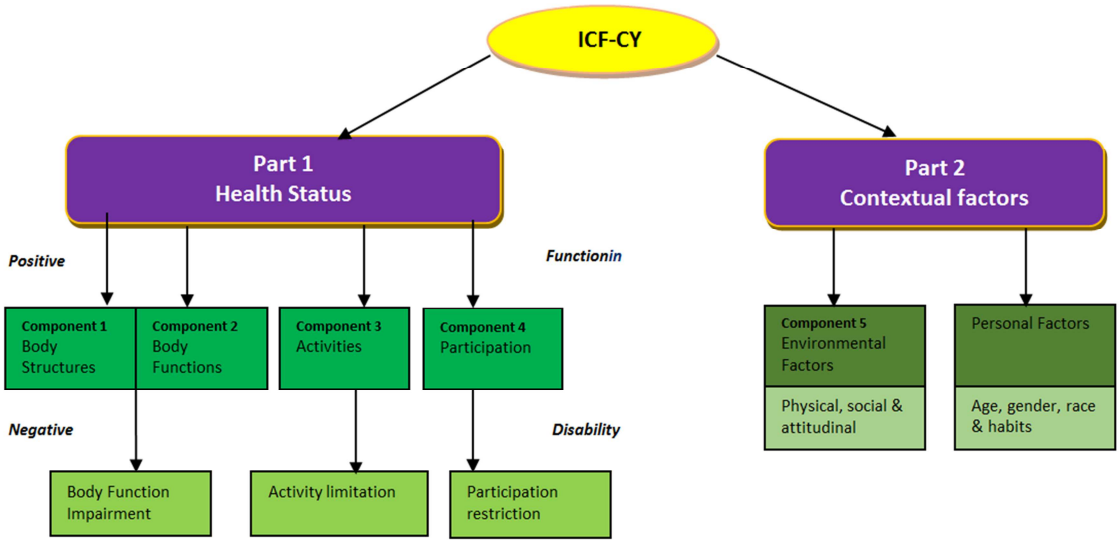

Figure 3. *Suggested structure of the ICF-CY as a classification: Adapted from Adolfsson, (2011).*

Components in the ICF-CY are operationalized through qualifiers. All components are quantified using a generic scale ranging from 0 (no problem) to 4 (Complete problem). Broad ranges of percentages are provided for in every step in the scale [30]. Body Functions are coded with one qualifier that indicates the extent or magnitude of the impairment in form of deviation, loss or delay. Body Structures are coded with three qualifiers: extent of impairment, nature of impairment

and location of impairment (*table 1*). Activity and participation are coded with two qualifiers while Environmental factors have also two qualifiers (*table 2*).

Table 1. *ICF-CY qualifiers for the body functions and body structures (WHO, 2007).*

BODY FUNCTIONS	**BODY STRUCTURES**		
Qualifier	**First Qualifier**	**Second Qualifier**	**Third Qualifier**
0 No problem	0 No problem	0 No change in structure	0 More than one region
1 Mild problem	1 Mild problem	1 Total absence	1 right
2 Moderate problem	2 Moderate problem	2 Partial absence	2 left
3 Severe difficulty	3 Severe difficulty	3 Additional part	3 both sided/ median
4 Complete difficulty	4 Complete difficulty	4 Aberrant dimensions	4 front
8 Not specified	8 Not specified	5 Discontinuity	5 back
9 Not applicable	9 Not applicable	6 Deviation position	6 proximal
		7 Qualitative changes in structure, including accumulation of fluid	7 distal
		8 Not specified	8 Not specified
		9 Not applicable	9 Not applicable

Table 2. *ICF-CY qualifiers for activity and participation and environmental factors (WHO, 2007).*

ACTIVITY AND PARTICIPATION		**ENVIRONMENTAL FACTORS**	
First Qualifier Performance	Second Qualifier Capacity	Barrier	Facilitator
0 No problem	0 No problem	0 No barrier	0 No facilitator
1 Mild problem	1 Mild problem	1 Mild barrier	+1 Mild facilitator
2 Moderate problem	2 Moderate problem	2 Moderate barrier	+2 Moderate facilitator
3 Severe difficulty	3 Severe difficulty	3 Severe barrier	+3 Substantial facilitator
4 Complete difficulty	4 Complete difficulty	4 Complete barrier	+4 Complete facilitator
8 Not specified	8 Not specified	8 Not specified	+8 Not specified
9 Not applicable	9 Not applicable	9 Not applicable	+9 Not applicable

6. Critique of the ICF/ICF-CY

"The *title* International Classification of Functioning, Disability and Health" is confusing to a lot of clinicians and worse still students. One may think that the classification of Functioning and Disability should be done first and thereafter classify health. The distinction between "*disability*" and "*functioning*" is not easily made, since there is no fixed limit or a "*gold standard*" to determine whether a person is disabled or not. The relationship between functioning and disability is quite abstract and besides, the two variables are not even shown in the framework. Furthermore, the component of health is one of the terms added by the WHO, and this has caused some confusions. The three variables of functioning, disability and health seem to be presented in a linear fashion and hence contributing to the challenges caused by the way of presentation. Of course functioning and disability are central ingredients of health, but the understanding can be disentangled in the process of assessment.

The overall term in the framework is functioning, which covers the components of body functions, body structures, activity and participation although functioning is used as a positive or neutral word and the negative aspect is called disability. However, it is practically difficult to come up with a composite value that truly reflects the functional status of an individual being assessed especially if the results are in the negative. This limitation may create potential difficulties in judging the relevance of contextual factors in the understanding of functioning, disability and health especially in diverse cultures. Even though the importance of contextual factors is reflected in the ICF and other conceptual disability models, the description of contextual factors seem to have focused on the type of factor, rather than on their potential roles in the disability process of individuals.

Nordenfelt [36] also critically analyzed the conceptual platform of the ICF, focusing on the definitions of Activity and Participation. He concluded that the ICF framework areas rest partly on the confusion between capacity for action and the actual performance of that action therefore, it is possible that different practitioners may interpret the scores in contrasting ways. Furthermore, Imrie [37] also evaluated the theoretical underpinnings of the ICF, arguing that the ICF fails to specify in detail the content of some of its main claims about the nature of impairment and disability, which may limit its educational capacity and influence.

The activity domain covers aspects of changing position, maintaining body position, fine and hand movement and walking. The participation domain provides codes to document the extent to which persons with physical disabilities experience engagement or restrictions in participating in some chores of domestic life like sweeping, washing and cleaning dishes expected for age and gender (d2100). The environmental domain allows coding facilitators or barriers to such involvement like support and relationship (e575) for example. Classifying the functional characteristics of physical disabilities across these dimensions can yield individual difference profiles from which needed supports or resources can be identified. For instance, the documentation of person–environment interaction in a child with SB could serve as the basis for intervention planning to promote an individual's skill performance and participation although the personal factor is a qualitative evaluation that can bring potential differences

with regards reliability.

While coding is very cardinal in tools for the purpose of standardization, the ICF coding can be seen as having a critical problem, which needs to be addressed in further studies, in addition to the question as to whether the use of different coding guidelines gives the same output in statistics and records. Various codes may have different implications for different care settings in practical terms, and individual ICF items requires validity and reliability studies in application to diverse populations thus causing practical problems in the use of the tool universally. For instance the code for "walking short distance" may be the same universally, but the "performance qualifier" would attach a different measurement due to cultural implications. Walking two blocks of flats may be considered walking a short distance in one society in the developed world whereby, walking for about 2km can also be considered short distance in the developing world. The views of the author of this paper are also shared by some other researchers who have noted that the reliability of the ICF codes as measured with qualifiers is relatively low, and the ICF Checklist requires modification [38]. Improvements can be achieved by selecting the most relevant items for each measurement and constructing appropriate qualifiers for each code according to the interest of users.

It is also important to note that the ICF is not a *measurement instrument*, but a *classification system*. The ICF-CY is a conceptual model that gives a framework for the development of methods and scales for measurement in children [31, 39]. Thus, it is extremely difficult to speak of the validity in the ICF model. For instance, a study was done that examined the test-retest reliability of ICF codes, and the rate of immeasurability in long-term care settings of the elderly to evaluate the clinical applicability of the ICF and its qualifiers, and the ICF checklist. Results of the study showed that the reliability of the ICF codes when measured with the current ICF qualifiers is relatively low. It was noted that the ICF checklist contains some items that are difficult to be applied in the geriatric care settings [38]. Nevertheless, it is possible to speak of logical coherence and structural clarity of the ICF conceptual model and of the validity and reliability in instruments constructed on the basis of ICF and ICF-CY [29].

7. Conclusion

Although the ICF-CY is a good conceptual model for rehabilitation medicine and good starting point for instrument development, it has its own weaknesses. Some of the major problems are linked to psychometric adequacy where some researchers have doubted its reliability and validity hence may not be used in totality as a measuring instrument, but as a screening tool that classifies. Since the ICF-CY provides a framework and a structure for collecting and organizing information, it may influence assessment, intervention planning, and the preparation of outcome evaluation.

Using the ICF-CY framework could enhance holistic management for children with disabilities and may also guide researchers and clinicians in their selection of an outcome measure for use in a study and/or clinical practice although standard approaches to the evaluation of activities and participation, and environmental facilitators and barriers are required. This could eventually aid clinicians working with children in need of specific support to enable their participation in everyday life activities. The ICF-CY framework clearly has demonstrated the focus of current management practices, as well as strengths and weaknesses in actual practices of childhood rehabilitation.

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