

**LINKING FUNCTION TO A DISEASE CLASSIFICATION FOR CHILDREN WITH
DISABILITY**

by

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ABSTRACT

The ICF-CY is the first universal classification system of child health and disability. This classification allows tracking child health and development through a common language and shared conceptualization across professional disciplines and countries. In addition, it is also the first unifying framework that attempts to describe the effects of context and environment on child functioning instead of just a medical case. The ICF-CY is an inclusive classification for health and health-related states including disability. It can be used to record the characteristics of developing children for the multiple purposes of public health, such as use in program planning, surveillance, research, and documentation of intervention outcomes in any setting and country.

The public health significance is that the ICF-CY provides a framework that can be adapted internationally by caring and dedicated professionals, community workers, government and health agencies, and children with disabilities and their families to advance thinking about how to best help those with disabilities live their life to the fullest and become integral members of their societies. Furthermore, providing a coding framework for worldwide health data can add to a universal database of information about disability that allow for research across nations, medical services, administrations, and time. Therefore, if people lived in environments that were more supportive of them, the Disability-Adjusted Life Years would go down, and productivity would go up. Children with disabilities are human beings. They deserve a good education and health care

just like everyone else. With a classification system that sees them only as medical problems and not as people who live in this world, they will never be equals.

Future research and implementation efforts with the ICF-CY promise to (1) revolutionize the way stakeholders in health care delivery systems think about and classify disability, (2) improve the quality of health care for individual with disability across the world, (3) generate innovative disability outcome-based research, and (4) influence culturally sensitive global health policy on disability.

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PREFACE

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1.0 INTRODUCTION

Classifying childhood disability is a challenge in clinical practice, research and education. Differences are in the methods and criteria used to diagnose, identify or classify disability across professional disciplines and countries. This is due to an absence of an all-inclusive meaning of disability. Therefore, in regards to children with disability, it has been the primary challenge in establishing a standard classification system.

The World Health Organization (WHO) Member States endorsed the International Classification of Functioning, Disability, and Health (ICF) as a universal framework for measuring health and disability. Guided by a biopsychosocial model, a combined and accepted model of the medical model and social model, the ICF was designed to provide a common standard classification system of health for adults including categories representing functioning at the body, person, and social levels. An ICF version for children and youth, from birth through 17 years, the International Classification of Functioning, Health, and Disability for Children and Youth (ICF-CY), became available in 2007.

The ICF-CY is the first universal classification system of child health and disability. This classification allows tracking child health and development through a common language and shared conceptualization across professional disciplines and countries [1]. In addition, it is the first framework to describe the effects of context and environment on child functioning. The ICF-CY

is an inclusive classification for health and health-related states including disability. It can be used in program planning, surveillance, research, and documentation of intervention outcomes [2].

1.1 THE PUBLIC HEALTH NEED

Public health began to reduce mortality by knowing the why, how, and the number of deaths [3-5]. The International Classification of Disease and Related Health Problems (ICD) became the primary data collection system for mortality data and indicated the public health activities.

Many authors have noted that public health has been relatively slow to respond to the health needs of those with disability for at least two reasons: public health emphasizes reducing mortality and morbidity, which is a failure of the public health system to prevent conditions associated with disability; and public health has no standard classification and coding system that can capture data and assess the multidimensional nature of disability, paralleling ICD's mortality and morbidity [4]. With the ICF/ICF-CY, these two reasons should no longer be an excuse to delay responses to the health needs of those with disability. As part of an early intervention or special education program, the special education system often needs public health professionals to support, evaluate, or provide interventions for children with disability [3, 6]. Therefore, a determination of a "disability status" can be done by incorporating the ICF-CY to determine access to appropriate public-funded programs such as early intervention programs and Medicaid [3, 6].

1.2 PUBLIC HEALTH SIGNIFICANCE

If we have available a classification system for disabilities that is comprehensive, that acknowledges that though there are things wrong with people's bodies, they can still be productive, we can create a context that is welcoming and accommodating.

If people lived in environments that were more supportive of them, Disability-Adjusted Life Year (DALY) would go down, and productivity would go up. People with disabilities are people. They deserve a good education and health care just like everyone else. With a classification system that sees them only as medical problems and not as people who live in this world, they will never be equals.

This essay discusses the potential of the ICF-CY (with the ICD when needed) in public health to address problems in classifying child health and disability. The background chapter is divided into two sections, the first one detailing disability to understand better the issues of definition, language, disparities, and measurement. The second section goes over the models that influenced the classification history of the current practice of "diagnosing" disabilities in children. The third chapter highlights the ICF/ICF-CY's framework, global impact, utility, and implementation issues. The discussion chapter explores the importance of this classification and the future direction of this classification system. Lastly, the conclusion of the essay emphasizes the need to incorporate a functional classification into current practices to improve advocacy, disparities, health, and disability measurements in children worldwide.

2.0 BACKGROUND

As of 2004, it was estimated that some 93 million children, or one in 20 (5 percent) of those aged 14 or younger, live with a disability of some kind [7]. Such global estimates are essentially speculative since they are outdated and derived from data that is varied by different methods to be considered reliable [7]. Depending on the place and time definitions of disability differ from methodology and analysis. According to a recent publication by the United Nations (UN) Children's Fund, the overall prevalence rates of child disability ranges from 0.4 percent to 12.7 percent with the estimates of prevalence rates varying by study, definition, and measure selected [8].

In 2010, about 2.8 million of an estimated 53.9 million school-aged children (aged five to 17) in the United States (U.S.) were reported to have some sort of disability. About 5 percent of school-aged children living in metropolitan areas across the U.S. had a disability, compared with 6.3 percent of children living outside metropolitan areas [9]. The authors of this report said there were some issues in the reporting of disability and the type of disability due to the various definitions of *disability* and did their best to capture the true numbers. These estimates are presented using data from the 2010 American Community Survey.

2.1 DISABILITY

2.1.1 Definitions of Disability

Defining *disability* is a very challenging undertaking. There are many ways to define this term. Many authors suggest that the concept itself is a slippery one for mainly two reasons.

First, in the past century the term *disability* was used to refer to a trait of a distinct class of people. The term “inability” has been used as a synonym to refer limitations on rights and powers. In the early 1990s, *disability* was defined as “any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being” (p. 5) [10]. In 2006, the Oxford English Dictionary recognized only these two for the term [11].

Second, many different conditions are considered disabilities such as deafness, blindness, diabetes, autism, epilepsy, and depression. Furthermore, disability includes diverse conditions such as the congenital absence or loss of a limb or a sensory function, progressive neurological conditions, chronic diseases, the limited ability to perform cognitive functions, and psychiatric disorders. Therefore, the definition varied for public services and organizations excluding the functional states of people with these various conditions.

Two features stand out in most definitions of *disability*, such as those of the WHO and the Americans with Disabilities Act (ADA): (i) a physical or mental characteristic labeled or perceived as an impairment or dysfunction, and (ii) some personal or social limitation associated with that impairment [2].

The all-encompassing definition of the WHO's ICF is used for the purpose of this thesis. According to this definition, *disability* is “an umbrella term for impairments, activity limitations, and participation restrictions. Functional restrictions occur as a result of the interaction between

an individual (with a health condition) and that individual's contextual factors (environmental and personal factors)” (p.17) [2]. *Impairments*, as indicated by the ICF, are the manifestations of dysfunction in the body structures or functions [2].

It is important to note that for the articles referenced and in the ICF definition, *disability* has been considered in aspects both visible and non-visible unless specified. Non-visible disabilities are those that are not readily obvious to the public eye, such as learning disability.

2.1.2 The Language and Terminology of Disability

To better understand the difficulty in defining *disability*, it is useful to examine the impact that language has had on people with disabilities. In social equality developments around race, gender, nationality, and sexuality, terminology has been a foundation of accomplishing acceptance and integration; therefore, so should language in the disability sector be seen as a tool for making these gains. Many confirm that language has had an adverse impact on people with disabilities for a long time. Descriptions of this population tend to label them as ill or ‘sick’ [12]. For a group of individuals who have been constantly depicted in vilifying, reductionist, and exclusivist terms, terminology matters significantly. The term *disability* has supplanted the most commonly used titles such as spastic, handicapped, and crippled [13]. An individual with a physical or intellectual disability, then, was said to be “handicapped” or “retarded” reflecting the lowered expectations of society [14]. Until the 1960s, terms such as “crippled” and “handicapped” persisted. A disability advocate researched what these terms meant. For instance, the term “cripple” is derived from “creep,” and “handicap” is an old term used to describe “cap-in-hand” begging [15]. The term *mental retardation* is no longer accepted in the U.S.; instead “intellectual disability” is the preferred replacement.

Following these changes, several attempts were made to introduce language that did not present the disability as the primary characteristic, called The Person First Movement [16]. This movement has added another layer to the change in language by requesting that individuals with disabilities be recognized first as people. “Person First Language,” refers for instance to “a person with a disability” rather than “a disabled person,” is intended to encourage the purpose of the social model by uprooting stigmatization [14]. While this may sound promising as it places the person before the disability, a disability-first approach persists; therefore, it is necessary to include this subsection so that readers are aware of the most appropriate language and terminology used for persons with disabilities.

2.1.3 Disparities of Disability

Just as there is a struggle to change the language and terminology around how persons with disabilities are addressed, disparities in this population exist. The number of individuals with disabilities has increased in recent decades and is likely to continue [17]. Age and other variables are closely linked to disability, for example, education, income, and race [17]. Poverty is also associated with disability since poor individuals may not have access to prenatal care, medical services, or insurance. In addition, poor people may be more exposed to unintended harm or violence [17].

2.1.3.1 Health Care Access

In the U.S., health insurance coverage is a critical avenue for gaining access to health care. People with disabilities in the U.S. appear to be as likely as people without disabilities to have health insurance [18]. However, people with disabilities are more likely to obtain insurance through a

public program of Medicare and Medicaid, and less likely through a private plan. Benefits restrictions and limited provider availability for public programs are well-documented [18].

Access to health care is necessary for maintaining good health and functioning, particularly for people with disabilities, who are at higher risk for conditions that may compromise health [18] such as poor oral hygiene. Yet people with disabilities report having more unmet health care needs, receiving fewer preventive services [19, 20], delaying health care due to cost [19], and being less satisfied with care [20] than people without disabilities. Women with physical disabilities report high rates of physicians refusing to treat them, and difficulty finding doctors to care for them during pregnancy [21]. Adults, adolescents, and children with intellectual disabilities experience more difficulty in finding, getting, or paying for health care [18]. Medicaid Supplemental Security Insurance (SSI) enrollees with disabilities report longer travel time to providers, less courteous providers, and overall less satisfaction with their health care than non-SSI enrollees [22].

Disparities in health care access are complex, ranging from health insurance to service provision differences [18]. There is evidence for differences in health care provider behaviors, clinic site and medical equipment inaccessibility, transportation difficulties, and availability and accessibility of health information for persons with disabilities [5].

2.1.3.2 Health Promotion Programs

Disparities occur due to lack of availability and accessibility of health promotion for people with disabilities, compared with the general population. This in turn likely serves to compound existing inequalities in health outcomes, as people with disabilities have fewer opportunities to maintain health and prevent disease [18].

2.1.3.3 Health Behaviors

There are also recognized disparities in healthy behaviors practiced by adults with disabilities. For instance, adults with disabilities have a higher rate of cigarette smoking and lower participation in physical activity and exercise [18]. It is estimated that adults with disabilities are about 50 percent more likely to smoke cigarettes than adults without disabilities [23]. Results from the National Health Interview Survey indicated that 36 percent of adults without disabilities reported no leisure-time physical activity, compared to 56 percent of adults with disabilities [18].

2.1.4 Measuring Disability in Children

There is a need to understand better the distribution (prevalence rate) of and frequency (incidence rate) for childhood disability [24]. Measuring child disability is difficult because disability is experienced differently depending on the society's norms. Therefore, surveys to measure disability must consider: the influence of contextual factors (e.g., transportation, accessible schools, and health care); culturally-based beliefs, attitudes or social stigma associated with disability; and the inconsistency in terms used to describe the experience and cause of impairments [25]. Such information is important to monitor the frequency of disability.

In both developed and developing countries, prevalence is used instead of incidence since data on the incidence of children disability are infrequently available. The prevalence rate is the proportion of people in a population who have a particular illness or condition at a specified point in time, or over a specified period of time. The numerator includes new cases and old cases (people who remained ill or had the condition at the specified point or during a period of time). A case is calculated in prevalence until death or recovery happens. This makes prevalence different from incidence, which includes only new cases in the numerator. The incidence rate is a measure of

frequency that an illness or condition occurs in a population over a period of time. Since prevalence is a function of both incidence (new cases) and survival (old cases), it might be confused by factors related to only survival. Therefore, prevalence rate, due to the lack of incidence data (new cases), has been used to describe the distribution of disability with only old cases that were identified a long time ago [26]. Thus, prevalence should be interpreted with caution for estimates of disability

In relatively developed nations, children are most often identified with a disability in educational and medical settings or through registries [24]. In many developing countries such infrastructure is lacking, resulting in a scarcity of information about children with disabilities due to inadequate identification [27] and the misconception that disability is not a major global health and human rights concern [28].

Estimates of disability prevalence rely on other methods to assess the occurrence of disability when schooling and funded services for children with disability are lacking [26]. Methods of inventory include informant reporting, population census surveys, and household surveys. Research indicates that the informant approach tends to be ineffective, unlike the other two methods, due to inconsistent definitions and classification codes (e.g. ICD) on the function of each child by teachers, health care providers, public health professionals, or other community members to identify children with disabilities [26].

2.1.4.1 Disability-Adjusted Life Year (DALY)

A DALY is often used as a marker for surveying the relative impact of public health interventions for individuals with disability [29]. DALYs, instead of utilizing only mortality, measure the effect of living with a disability [29]. A DALY can be defined as the incidence of “healthy” life years that is lost due to a disease, disability, or early death [30]. DALY includes non-fatal and fatal outcomes. Therefore, DALYs are calculated as the sum of the Years of Life Lost due to premature death

(YLL) and the Years Lost due to Disability (YLD) [30]. With the implementation of DALYs, conditions that were non-deadly but critical to disabilities rose in significance in the field of public health.

While many authors and researchers have evaluated the approach exemplified in DALYs [31], others have focused on the DALY's weakness to record improvement in the functioning of individuals with a disability, suggesting that DALYs do not correctly represent disability and do not improve a person's medical diagnosis [32]. DALYs do not reflect adjustments in individuals' functional status or health if they get rehabilitation services, assistive gadgets, housing or live in a society that is more open and accessible to people with functional impediments. DALYs simply reflect the incidence of a medical condition that is connected with certain functional limitations [32].

A few models of disability have impacted the professional mindset throughout the years: the medical, social, and biopsychosocial. The next section of this chapter details these models, as they identify and assist us in understanding the contemporary meanings of disability, health, and functioning as indicated by the ICF/ICF-CY.

2.2 CLASSIFICATIONS OF DISABILITY

2.2.1 Models of Disability

Conceptual models and frameworks of disability, disease, and health conditions have been used by clinicians and researchers to describe, assess, and measure individuals' and populations' health. They provide a common understanding and clear, concise communication of human functioning

and health. Although there are many conceptual models and frameworks utilized by various professional disciplines, three models are the most influential: medical, social, and biopsychosocial [33].

The traditional way of conceptualizing disability, disease, and health conditions and identifying intervention strategies was dominated by two models (medical and social) that were later merged to form a third model [34]. The *medical* or *biomedical* model interprets a health condition or disease as a personal or individual problem directly caused by disease, trauma, or other health condition, which requires professional medical care. In contrast, the *social* or *psychosocial* model considers a health condition as a socially-created problem rather than only the individual's. The merging of the two models shaped the *biopsychosocial* model, which identifies both the individual's biological aspects of health and the individual and social contexts of a person's health [33, 35]. The integration of the first two models, the biopsychosocial model, led to the development of the ICF [36].

2.2.1.1 Medical Model

According to the medical model, disability, health, and functioning are identified by objective physical characteristics of a person. Therefore, *disability* results from impairment of anatomical structures that result from an ailment or physical injury, *health* is the non-appearance of ailment, and *functioning* is defined as the physical capacity and performance after impairment. The medical model proposes that disability is a “problem” with the individual that can be assessed and characterized or analyzed and is the focus of a health care services intervention that looks to improve or alleviate the condition. This model concentrates on the diagnosis and treatment of malady, disorder, or injury [2].

The ICD is an example of the application of the medical model, which has had an impact on the characterization of health [37]. The ICD provides an etiological (relating to causes) classification of health conditions identified with mortality and morbidity. A developing body of research recommends that indicative data alone may not satisfactorily reflect a person's health condition [38].

2.2.1.2 Social Model

Despite the fact that the medical model continues to be influential, its restrictions and disability activism resulted in an alternative social model of medical services and disability. The social model of disability, health, and functioning considers the environment as the “real determinant of individual functioning” (p. 281) [39]. It views disability as a social construct and impairment as it exists in a given context in the public eye and proposes that the concept of disability is not problematic but rather societal attitudes are. Health status is not restricted to being an individual quality; it incorporates the association between the individual's functioning and the environment [40, 41], which is influenced by societal norms and barriers. The social model is preferred over the medical model by promoters for the civil right of persons with disability [38]. From the social model perspective, it is vital that inequalities resulting from the experience of disability be identified, measured, and alleviated.

2.2.1.3 Biopsychosocial Model

In 1977, George Engel developed the biopsychosocial model, a model of health care and disability that fuses aspects of both the medical and social models [42]. It incorporates medical data, collected from health professionals, with the social aspects of life [38], giving equal weight to all variables affecting health and functioning. The point of view of this model is complementary to

contemporary medical procedures and methods [42]. The biopsychosocial model does not diminish either the medical or social model's point of view but rather combines them into the contemporary classification of disability, health, and function.

The biopsychosocial model influenced the development of the International Classification of Impairments, Disabilities and Handicaps (ICIDH) into the ICF. The ICF's conceptual framework delineates how facilitators of the ICF and barriers in the environment contribute to and impact health and functioning. Consistent with qualities proposed by the social model, ethical utilization of the ICF requires that the person's evaluations of ecological resources and liabilities, individual body capacities, and ability to participate in individual and social activities are considered alongside expert classification of functioning, disability, and health [2]. The title change from ICIDH to ICF is predictable with the shift from an emphasis on the "consequence of disease" to "functioning as a component of health" (p.566) [36].

Improvement of the ICF and the ICF-CY have impacted by rehabilitation programs as well as by ideological and political advancements. As part of the classifications of disability, the ICF and the ICF-CY are recent developments in the history of disability and how disability is discussed.

2.2.2 History of Disability Classifications

In the 1600s and 1700s, attempts were made to classify diseases systematically. In 1893, the International Statistical Institute issued the first international classification of diseases, developed by French statistician and demographer Jacques Bertillon, called the Bertillon Classification of Causes of Death. Five years later, the American Public Health Association recommended that the system be revised every decade. Subsequently, Bertillon's classification became known as the International List of Causes of Death and later as the ICD. After 1948, the WHO took the

responsibility to publish the ICD and started to collect international data for epidemiological surveillance and health management purposes. The ICD became a core classification of the WHO Family of International Classifications (WHO-FIC), as did ICF/ICF-CY later on.

However, as mentioned before, many wanted to shift the view of disability away from medical definitions. In the 1960s, sociologist Saad Nagi developed a conceptual framework identified with the social model of disability. Nagi asserted that there was no obvious connection between ailment and disability – a person experiencing an ailment may encounter weaknesses but not a disability [43]. Disability may be affected by how the individual himself, as well as other people, characterize the circumstance. The Nagi framework was not a classification in and of itself but rather had an impact on the consequent classification frameworks of disability [44].

Building on the Nagi framework, a dynamic concept of disability was underlined in various models and hypotheses [44]. In 1972, the WHO recognized the restrictions of the ICD in depicting results of non-acute ailments [44]. In 1980, the ICIDH was developed [45]. The ICIDH was considered an improvement in the documentation of disability as it gave a medical model of disability on three levels – impairment, disability and handicap [46, 47]. Nevertheless, the ICIDH was scrutinized for the linear causal relationship from impairment to handicap, for disregarding the effect of the environment on the development of disability [48], and for the absence of a lifespan point of view of disability [46]. Disabled People's International (DPI) rejected the ICIDH definitions and accepted definitions identified with the social model of disability [44].

The modifications of the ICIDH brought about the Beta-2 draft, the ICIDH2. In 2001, the ICF was issued. Field trials of the ICIDH2 were with children [49]. WHO's International Task Force on Children and Youth, incorporating members of the medical, mental, social and educational professions, worked on the modification of the classification [50]. In 2007, the child

and youth adaptation of the ICF, the ICF-CY, was issued by the WHO. In the ICF-CY, children's reliance on the environment was considered. The ecological model of child development [51, 52], which focuses on the significance of environment for child development, guided improvement of the ICF-CY [53]. Child development perspectives were represented in the details of the classification. Definitions of the categories and the inclusion and exclusion criteria were amended and extended to cover areas of functioning and environment in childhood [50]. New categories were added to reflect, for instance, learning process, and behavioral change to diverse environmental circumstances [50]. The structure of the ICF-CY parallels the ICF; however, it contains additional areas of functioning and environment in childhood and adolescence.

Improvement of the ICF/ICF-CY began in the therapeutic setting and was impacted by the social model of disability and the human rights developments. Improvements include recognizing disability and the constraints it may bring about in regular activities [50]. Moreover, the fact that the role of environment in disability has been in every one of the classifications prompted inclusion of environmental factors in the ICF and the ICF-CY [50].

The essential child disability classification system in the United States records and outlines outcomes to determine a clear cut disability diagnosis. These diagnoses are in light of criteria laid out in the ICD.

2.2.3 Current Practice of Disability Recording

The ICD is the standard symptomatic classification for the study of disease transmission and is used for health administration and clinical purposes [54]. This incorporates investigation of the general health circumstance of populations [54]. It is used to capture morbidity and mortality rates and pervasiveness of infections and other health issues [54]. Doctors, medical caretakers,

suppliers, researchers, health information administration coders, health information technology experts, policy-makers, insurers, and patient associations can utilize the ICD framework [54]. It is applied to classify illness and other health issues that are recorded on health and vital records such as death certificates [54]. Furthermore, the ability to store and retrieve symptomatic data for clinical, epidemiological and quality purposes, allowed for the accumulation of national mortality and morbidity statistics by WHO member states [54].

When a physician evaluates a child for developmental disability or when a multidisciplinary educational team evaluates a student for a learning disability, for example, they collect subjective and objective data (the “history and physical”) to diagnose the patient’s condition and develop a plan for treatment [54]. The ICD is a coding system used internationally to classify morbidity and mortality data for vital health statistics tracking of diseases and signs, symptoms, and external causes of injury or diseases [54]. In addition, in the U.S. it is used for health insurance claim reimbursement. Since late 2014, the tenth revision of ICD (ICD-10) has been used. ICD-10 allows for specificity in describing a patient’s diagnosis and in classifying inpatient procedures so that insurance reimbursement can better reflect the diagnostic needs for the services rendered by the provider [54].

Public health and health experts have used the WHO's ICD-10 to report mortality and morbidity. In any case, this framework does not capture general individual health status [36]. The WHO’s ICF and ICF-CY frameworks provide an opportunity to integrate functioning information for each individual [36]. The next chapter goes into further detail about the framework, impact and benefits, and issues in implementation.

3.0 THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

Etiology of dysfunction is not the emphasis of the ICF, but rather it is the focus of its sister classification, the ICD-10; the ICF does not focus on the pathology itself. The ICF's definition of *disability* is intended to focus on the individual, societal, and body-related aspects of impairments, activity limitation, and participation restriction in the environment.

In the ICF, the term *health* refers to aspects of well-being that are ordinarily a focus of health care experts, for instance, seeing, hearing, speaking, recalling, learning, and walking. Further, the ICF represents health related aspects of well-being that are not commonly a focus for human services frameworks, for example, work, education, employment, social interactions, and transportation. The ICF was not intended to characterize disability solely; it groups health and health-related states such as disability [38].

In the ICF, the term *impairment* (an issue with a body function or structure) was reclassified as an *activity limitation*, and the term *handicap* was supplanted by the term *participation restriction*, referring to what an individual may experience in life because of environmental influences. Therefore, disability is represented with the terms *activity limitations* and *participation restrictions* [2].

3.1 THE CONCEPTUAL FRAMEWORK

The ICF has two parts, each with two components. The first part describes the Functioning and Disability of an individual, and the second part describes the Contextual Factors. The first part is further divided into two chapters known as Body Functions and Body Structures, and Activities and Participation. The second part is also split into two chapters called Environmental Factors and Personal Factors.

3.2 ICF-CY OVERVIEW

The ICF was developed to provide a universal method and common language for documenting dimensions of human health, functioning, and disability. However, the 2001 ICF was not sufficiently comprehensive to include health and functional characteristics in children, particularly those of early childhood [46, 49]. In contrast to the task of documenting functioning in adults, documenting child characteristics can be more challenging in that the developing child is a “moving target,” manifesting rapid changes in physical, social, and psychological functioning during the first two decades of life [49]. The development of the ICF-CY expanded the scope and content of the ICF to encompass the developmental characteristics of children and youth from birth through age 17, the age range used in another universal document, the UN Convention on the Rights of the Child [38].

In keeping with the ICF’s classification structure, new content was added to the four ICF-CY domains such as *adaptability* (b1250) in Body Functions and *acquiring language* (d133) in Activities and Participation [38]. These additions to the ICF-CY codes reflect the two

developmental chapters of Body Functions and Body Structures, and Activities and Participation of infants, toddlers, children, and adolescents. The use of a code provides for documenting the role of the environment to determine a child's functioning and development.

3.2.1 Global Impacts and Utility Benefits

The ICF/ICF-CY has been adopted internationally. For example, Canada embraced the ICF through the Canadian Institute for Health Information, and Australia with the Australian Institute of Health and Welfare [55]. Work on the World Health Survey, based on the ICF-CY system, has been undertaken in 74 nations [36]. In the United States, the ICF/ICF-CY has an impact on the speech-language pathology (SLP) field [56], affecting data collection, evaluation of medications, measurement of clinical examination results, and exploration of the role of communication in the quality of life [57].

3.2.1.1 Common Language Benefit

In 2008, Portugal integrated the use of the ICF-CY and its language into special education law and required that resources should be allocated to children with disability [58]. Research showed that the use of the ICF-CY in Portugal created richer descriptions of a student's functional limitations and environmental factors. One of the difficulties identified by education professionals when implementing the ICF-CY was the lack of health professionals to assess and describe information on the body functions and structures [59]. This suggests a link between resource allocation and medical assessment. The experience of Portugal illustrates that integrating the ICF-CY into an education system requires some thought and planning [59]. The experience in Portugal also further

highlights that the common language the ICF brings to education can facilitate its use by a multidisciplinary team.

3.2.1.2 Education Benefit

Since early 2011, Switzerland has used an ICF-CY-based procedure to establish eligibility for children with disability [60]. The ICF-CY was used to organize all information relevant to the provision of additional support and provide a framework to integrate different perspectives and data from various sources. Information is collected electronically and is then transmitted to the authorities responsible for efficient distribution of resources. This required different professionals to disaggregate and systematically enter all information relevant to the process of establishing eligibility such as categorical representation, functioning, environment, recommended educational and developmental goals, recommended professional environment, and estimate of requirements or environmental adaptations and needs [60]. The application of ICF/ICF-CY in Switzerland is an encouraging step toward the use of the ICF/ICF-CY in education as one of a variety of approaches that may be useful in the process of providing support to children with disability.

3.2.2 Clinical Practice Benefit

Following the medical model, diagnoses in clinical practice ordinarily take into account a number of symptoms within the extensive codes of manifestations provided by the ICD. Consider the following case study of a six-year-old child as an example to differentiate clinical practices of the two classifications, ICD and ICF-CY [61]: She has an interdental lisp, mild expressive and receptive language impairment, and a mild stutter. She is somewhat behind peers in learning to read; it has recently been suggested that the child has a mild attention deficit disorder. Although

each of these is considered to be mild at the body function level, combined they can contribute to problems with activities and participation in education and play. The child is in a regular class at school, and her teacher has implemented a remedial reading program. She is the second child out of three to a single mother. The mother receives low wages and works long hours. The grandmother often takes care of the children while their mother is at work. The child has a few close friends, but others at school tease her about her speech. The child lives in a small rural town that has intermittent SLP services.

If the child were evaluated using the typical medical model, the ICD would code only for the impairments, and each impairment would be looked at and treated separately. However, looking at the child's body function impairments, the activity and participation areas, and the environmental and personal factors shows a better understanding of this child and her functioning. The ICF-CY recognizes that environmental factors are facilitators and barriers that impact the child's ability to participate fully in life and that influence her getting appropriate health and education services. Environmental factors may also have an effect on personal factors in determining her outlook on life. Therefore, incorporating the ICF-CY components that are appropriate for the health and education goals for the child can be realized [53].

3.2.3 Issue in Implementation

Although the ICF-CY has applications in the health fields such as nursing, physical medicine, rehabilitation, and psychology [62, 63], there is still a major issue with the length of coding for each dimension. The ICF-CY has roughly 1600 codes. In the U.S., most health professionals do not have the time or resources to use such an extensive coding system [64]. Since the ICD has been

around longer than the ICF, clinicians have memorized the ICD codes that they most commonly use.

4.0 DISCUSSION

The concepts of health, disability, and quality of life are frequently used interchangeably in defining policies and practices on behalf of individuals with disabilities. The overall framework and content of the ICF-CY are consistent with an inclusive definition of disability and health.

A diagnosis alone does not predict service needs or length of hospitalization [2]. Neither does the presence of a disease or condition a predictor of receiving disability benefits. Therefore, only utilizing a medical classification of diagnoses will not provide the data and information necessary for health planning and management. What is lacking is data on functioning and disability. The ICF-CY makes it possible to gather those fundamental data in a consistent and universally equivalent manner because any child experiencing limitations of access to the physical, social or psychological environment or equality of opportunity is considered a deprivation of rights [2].

While public health has addressed the epidemiology of diagnoses associated with disabilities, little epidemiologic attention has been paid to related health issues, research on the natural course of secondary conditions, or efficacy studies that would improve the health and prevent secondary conditions among people with disabilities. Moreover, there are few mechanisms available to transfer research results into public health practice for this population or to conduct prevention research in the public health settings.

In spite of the fact that we have demographic variables, for example, age, ethnicity, race, and sex to portray fundamental qualities of the population, we do not have a comparative variable to recognize disability status. While each of the aspects of disability can be coded utilizing the ICF-CY and coding framework, developing a basic and direct way to deal with identifying

individuals with disability has not been a priority. This is an important public health need in the area of assessment. In the event that public health is to characterize individuals with disability and individuals without disabilities, a set of identification questions that can be incorporated in any survey, census, or questionnaire must be developed. This set could be utilized as a demographic variable, with age, race/ethnicity, and sex in data collection and analyzes.

In surveillance applications, a set of ICF-CY codes may be used to standardize data collection procedures across instruments and after some time keeping in mind the end goal to record prevalence and incidences of disability. In surveillance and research settings, there is a need to have common data to document the environment and distribution of functional limitations among children. Standardized documentation with ICF-CY codes could improve the accuracy of statistical databases with significant implications for recording the sort of assets utilized and for projecting future asset needs as a function of changing prevalence patterns. ICF-CY codes may be utilized to standardize assessment of the characteristics of participants, the choice of evaluation measures and the definitions of results.

4.1 FUTURE DIRECTIONS IN ICF-CY RESEARCH AND PRACTICE

The greatest contribution of the ICF-CY to public health is the opportunity for public health professionals, health care stakeholders, consumers, and providers alike, to participate fully in ongoing interdisciplinary cooperation to improve public-funded programs such as early intervention programs targeting children with disabilities to maximize their personal achievement and full participation in society. However, it is important to note that as a classification system, the ICF-CY is in its beginning stages of development.

Future research and implementation efforts with the ICF-CY promise to (1) revolutionize the way stakeholders in health care delivery systems think about and classify disability, (2) improve the quality of health care for individual with disability across the world, (3) generate innovative disability outcome-based research, and (4) influence culturally sensitive global health policy on disability [65].

In WHO's international classifications, health conditions (diseases, disorders, and injuries) are classified in the ICD-10. Whereas, functioning and disability associated with health conditions are classified in ICF/ICF-CY. ICD-10 and ICF/ICF-CY are therefore complementary, and users are encouraged to utilize these two members of the WHO family of international classifications together, not only the ICD as in the past [2]. ICD-10 provides a "diagnosis" of diseases, disorders or other health conditions, and the ICF enriches this information by focusing on functioning. Both information on diagnosis and functioning provides a more comprehensive understanding of the population's health, which can then be used for decision-making purposes.

5.0 CONCLUSION

Over a billion people, about 15% of the world's population, have some form of disability [66]. How disabilities are classified has been problematic, especially among youth. The development of the ICF and ICF-CY are definite improvements because they take into account not only the physical characteristics of people with disabilities but also the environments in which they live, work and play.

The ICF and the ICF-CY can be influential tools for research, clinical use, social and public policy and advocacy, and education. They are both a theoretical methodology to functional health problems and a classification system. The ICF-CY provides a framework that can be adapted internationally by caring and dedicated professionals, community workers, government and health agencies, and children with disabilities and their families to advance thinking about how to best help those with disabilities live their life to the fullest and become integral members of their societies. This classification system is a language to be used to produce inventive programs and eventually to self-improve the classification system. The ICF-CY can improve the epidemiology of disability, and guide better research and clinical efforts. The interdisciplinary aspect of the ICF demonstrates how important communication is to all of functioning.

The overall applications of the ICF-CY include enhancing the ICD coding by making appropriate profiles based on a person's functioning, disability, and health; improving communication between different users, such as health care workers, researchers, policymakers, and the public, including people with disabilities; data can be utilized to recognize facilitators and barriers that influence the full support and services of individuals with disabilities in the public eye. Furthermore, providing a coding framework for worldwide health data can add to a universal

database of information about health and health-related states that allow for research across nations, medical services, administrations, and time.

Children (along with adults) with disabilities were first seen as people with a medical problem that needed to be fixed. Then they were recognized as numbers related to statistical measurements and prevalence rate. Therefore, they were never represented correctly with the addition of incidence rate. These are people. They deserve a high-quality life. High quality means they have access to everything they need. And as long as we use a classification system that sees them only as medical cases and not as people who have functional issues, not only because of their bodies but also the way the world is built around them, they will never be equal. Using the ICF-CY framework, children with disability may no longer be seen as a problem or a number, but as human beings who deserve the right to be treated fairly in the broader context of their lives.

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