

2 Definitions

2-1 Introduction

Identifying a standardized definition for disability has been and continues to be an international problem.

Disability is one of the possible outcomes of the interaction between the biological being and the environment surrounding it. However, the effects of this interaction on the human being is not only governed by the biological outcome, it is modified and restructured through its interaction, once again, with the surrounding society and environment.

Hence, the way disability is defined by any society, at a certain time, reflects the way the society perceives the condition. This perception reflects, in its own term, the attitudes of the society and the way it is organised to deal with different people and groups within it. In addition, different “schools” or “professions” gave their own categories according to their particular relationship to the question and approach.

Consequently, different models or institutions of care, such as: Health, Social or Educational, tend to give their own interpretation to the phenomenon.

The “Biomedical Model” tends to describe it from the point of view of the aetiology, or from the point of view of describing the physical or physiological characteristics of a “condition” which is deviant from the “norm”. Hence, *disease oriented categories* for disability were often the terms used by certain countries in their censuses. These terms ranged for example from respiratory and circulatory in a survey conducted in Australia in 1981, to Tuberculosis (TB), Leprosy, Onchocerceri (River Blindness), Sleeping Sickness in Mali 1976,...etc. In other instances, descriptive terms were used, such as: hunchback, paralysed and crippled in Turkey 1975 (Yu, 1991). For many years, categories such as idiot, moron, imbecile, were internationally used to describe the degrees of mental retardation.

On the other hand, institutions such as insurance or social services tended to define it from the view of the degree of incapacitation produced by the disability; i.e., inability to get a job and hence, their entitlement for allowances and/or financial support.

However, these various definitions gave rise to many problems. Among these problems the following ones stand out:

- **Statistical problems:** Different population censuses or surveys using different categories within the same country or across different countries gave rise to great discrepancy in the statistical data compiled.
- **Labelling:** These definitions held in many instances negative connotations and tended to stick labels on people, which augmented their isolation and treatment as outcasts instead of recognising their abilities and integrating them.
- **Narrowing of interventions:** Disease-oriented definitions tended to narrow the phenomena. They concentrated on treatment and cure, or on rehabilitating the individual, rather than on the consequences of the negative social attitudes and environmental barriers. The latter, in many cases constituted the most handicapping conditions facing the person with disability. On the other hand, definitions which viewed the problem mainly from the point of view of incapacity to work, disregarded the other special needs of the disabled particularly within the child population.

2-2 Definitions in Egypt

The first formal recognition of disability and the role of the state towards the disabled in Egypt was declared in 1950 through the law number 116. The law came in the aftermath of the 1948 International Human Rights Declaration which was adopted by the state. The declaration recognized the right “of all people for social insurance in cases of unemployment, disease and *incapacity*, and aging” (Mahmoud, 1994).

The law did not give a clear definition, but described it from the point of view of those whose physical condition incapacitate them from work. Hence, it was narrowed to adults who acquired a condition which made them unable to work; a fact which excluded children and the vast majority of women who at the time had no formal employment.

Although several pieces of legislature concerning the disabled followed this law (this will be discussed later in the coming chapter), it was not until 1975 that a formal and a more elaborate definition of disability was developed by the state.

The formal definition of disability:

According to the law of 1975 No. 39, “*The disabled is any person unable to depend on him/herself in carrying out **their job or in carrying out another job and maintain it**, and that his/her abilities to do that, has decreased as a result of a physical or sensory or congenital impairment and that this individual has become inflicted with a handicap which impedes his coping with his society or environment and prevents his success in life*” (MOSA - Internal Statute, 1980, cited in Osman H. 1988).

Although the definition is to be considered an achievement, it still leaves a lot to be desired. Disability is still described according to only one of its social outcomes; i.e., inability to work; and hence, eligibility to aids and pensions. It is still restricted to the adult world and mainly the male’s. It encompasses only the severer forms and does not put on itself the task of responding to the various special needs of the disabled person and particularly the disabled child.

2-3 International development in defining disability

Within the above context, and within the context of the growing interest in chronic ill-health and disability, particularly in the North, a new international classification was developed by the WHO in 1980; namely the classification of Impairments, Disability and Handicap.

The classification attempted to overcome the problems of the available medical classifications which came “short of describing the complex manifestations of the consequences of disease particularly for chronic and progressive or irreversible disorders.”

The WHO manual, in reality provides three distinctive classifications which describe these effects on three different planes, namely:

- The problem as experienced on the level of the organ “impairment”; i.e., the presence of a pathology which has special manifestations. The problem is hence “exteriorized”, meaning: people can recognise its manifestations, but not necessarily so, if it has not yet affected the function (or functions) which this organ or system acts upon. The study of Ain Helwan has shown, though debatable, that the real significance of the term ‘impairment’ is when there is a condition in its latency state;

i.e., before it has manifestly affected the function, and when early detection is of significance.

- The problem as experienced on the level of the function “disability” ;i.e., when the impairment impedes an activity which is normal to the age and sex of the person. The problem is hence “objectified”, meaning: it is an objective phenomena which the person and others can recognise through its manifestations in the activities.
- The problem as experienced on the level of the social roles “handicap”; i.e., when the disability prevents the person from taking on roles which are appropriate to their age, culture and sex. The problem is hence, “socialised”, meaning: the problem is an outcome of the interaction of the disability with the societal attitudes and social system. The more the society is open for the disabled, recognises their rights and provides for them, the less the condition will become handicapping (WHO, 1985).

2-4 The value of the WHO definitions in the current study

In spite of the shortcomings of the classifications, particularly their complexity, the definitions constitute an important achievement. They have, for the first time, provided internationally standardised definitions which help in cases of **comparability**.

The classification helped to clarify the complexity of the phenomenon, by describing its actualisation as a process which is realised at different levels. By doing so, the classification helped in identifying different levels of interventions, such as: prevention, early detection, rehabilitation and equalisation of opportunity.

By separating the phenomena of ‘handicap’ from ‘disability’, an important emphasis for the first time was given to the societal attitudes and its organisation vis-à-vis the disability.

The *disability* level or plane of experience identified by the WHO classification as a decrease in function or activity, provides us with a criteria which can easily be agreed upon and its degrees assessed. For example, the degree of decrease in specific abilities, such as listening, walking or seeing...etc.

Meanwhile, assessment of health services can give an idea of the role played by them in preventing disabilities and their early detection, hence identifying *impairment*.

Suggested definitions for the study:

As the study aims at comparing social policies and institutional forms of care for disabled children, the two levels of the experience; i.e. the *disability* and the *handicap* as defined in the WHO manual, will be our points of reference. In other words, services will be assessed according to their response to the needs of children on the level of disability as well as handicap.

Therefore, from the practical point of view, we will be looking at:

- how much and in what way available networks of services provide for the loss or decrease in the functions or activities produced by the disability, and,
- how much services, legislature, media, ... etc., respond to the problems of the social and environmental barriers which hamper the integration of children in their families and societies.

2-5 Categories of childhood disabilities suggested:

In spite of the development in the basic definitions given in the WHO manual, the detailed classifications of each plane are extremely complex and have shown, in many surveys, not to be of practical value (Thorburn et al, 1991 and Shukrallah, 1997).

However, the basic definition of disability, i.e. a decrease in a specific complex function such as hearing, moving, seeing or understanding provides the clearest measurable entities so far.

In the International Epidemiological Study of Childhood Disability (IESCD), a simplified list of categories was adapted from the International Classification of Impairment, Disability and Handicap (ICIDH).

In the Ain-Helwan study for many reasons, among which stood the aim of helping international standardisation, the same basic categories were used.

In this study we suggest to use these categories of childhood disabilities adopted from the above mentioned study and tested in the Ain-Helwan Childhood Disability Survey (Shukrallah et al, Sept. 1995):

Table 4: Suggested Categories of childhood disabilities:

Categories	Definition
1. Motor disabilities including;	Decrease or difficulty in the ability to
○ Fine Motor	○ Manipulate and the use of hands and fingers
○ Gross Motor	○ Sit and balance ○ Move
2. Hearing	Decrease in ability of hearing
3. Speech	Difficulty in ability to speak
4. Vision	Difficulty or decrease in ability to see
5. Cognitive	Difficulty or decrease in ability to understand
6. Fits or Seizures	Momentary loss of consciousness which is accompanied by jerking movements of muscles
7. Multiple Disabilities	Difficulty or decrease in two or more abilities excluding speech as secondary to MR or Hearing

Table 5 showing criteria for measuring the above disability categories according to the three stages of severity; namely , mild, moderate and severe:

Types and Categories	Degrees					
	Mild		Moderate		Severe	
Motor						
<i>Fine motor</i>	Some difficulty. Grasp may be weak or crude but can hold most instruments (pen, knife, glass,...etc.) Can dress oneself May not be able to fully raise arms above head		Difficulty in holding implements and using arms for dressing unable to pick up small pill. In hemiplegia one hand completely useless		Does not use either hand for anything for more than reaching or pointing.	
<i>Gross motor</i>	- some difficulty in prolonged sitting - does not need support		Needs support to sit upright		Unable to maintain balance in upright position without full support	
	walks unaided - may have a limp or walk with an artificial limb. May have difficulty in climbing steep steps or drags foot		Needs maximum aid to walk, but still can move about		Cannot walk at all	
Hearing	by Db	by Behavioural parameters	Db	Behaviour	Db	Behavior
	20 - 50 Db loss in best ear	Some difficulty in hearing. Needs to be placed in front of class. Understands normal speech, speaks normally. May wear a hearing aid.	50 - 70 Db loss in best ear	Difficulty in hearing speech even with hearing aid. Affects expression of speech	No response	No useful hearing evident
Speech	Speaks in sentences (depends on age). Can be understood but speech is not sophisticated enough to get more than simple ideas across.		Speaks in single words only which can get across basic needs		No speech at all	
Vision	Measurements	Behavioural features	Measurements	Behavioural features	Measurements	Behavioural features
	Can see Chart with pinhole	Corrected by glasses Can get around without difficulty	6/18 or 20/60	Not correctable by glasses	6/60 or 20/200	No vision except light Needs cane.
Cognitive	IQ 50 - 69		IQ 49 - 35		I Q 34 - 20 in addition to profound <20	
Fits or Seizures	2-4 Fits per year		1fit /week to 1/3 fits months		More than 1 fit /week	
Multiple disability	A mild decrease in 2 or more of the above mentioned functions		A moderate decrease in 2 or more functions		Severe decrease in 2 or more functions	

