## بسم الله الرحمن الرحيم University of Khartoum Faculty of Economic and Social Studies Department of Econometrics and Social Statistics MS.c In Econometrics and Social Statistics 2002-2004

# **Demography of Disability in Sudan**

M,S.c partial fulfillment dissertation.

Submitted by: Dalia Abbas El Mubarak Abu-Shama

Supervisor: Dr. Osama Ali Abu-Zeid

**December 2004** 

(٣٥)

## Acknowledgements

The auther wishes to express his deep sense of gratitude to Dr. Osama Ali Abu-Zeid, for his valuable guidance keen interest and encouragement throughout the preparation of this research.

The auther is very much indebted to her family for their patience and help enabling to carry out this work.

The assistance given by the staff of the Department of Econometrics and Social Statistics is also greatly acknowledged.

#### **Abstract**

There is a large and growing number of persons with disability in the world today. In most countries at least one person out of ten is disabled. To a large extent, disabled persons are exposed to physical, cultural and social barriers which disabled their lives even if rehabilitation assistance is available.

As there are few studies about disability in this country, the study is an attempt to shed light on the status of population of disability in Sudan, and the challenges they are facing.

Descriptive statistical analysis was used to analyze the differentials of disability rates in Northern Sudan using 1993 population census. Results show that almost 1.59% of the population having disability. Disabilities among males are higher than females and the disability rates in the rural areas are higher compared to those in urban areas.

Theoretical analyses were conducted showing different concepts and definitions and linkages of disability with other factors such as poverty, education and employment.

The concepts of disability from an international perspective were studied showing the role of the international organizations and the levels of disability in selected developing countries.

In addition, the national policies and strategies and support services provided by the government, National non-governmental organization's (NGO's) and foreign organizations were also covered.

Finally, the study recommends that systematic information about disability in all states of Sudan should be provided, to adopt a policy and supporting structure of services. Also in the next population census, more questions should be added covering all aspects of disability. As that will help for further comprehensive research in this field in the future.

# ملخص الدراسة

1998

1,09

# **Table of Contents**

	Page
Acknowledgement	I
Abstract in English	II
Abstract in Arabic	III
Table of Contents	V
List of Tables	VI
1. Chapter One: Introduction	1
1-1 Background	1
1-2 Research Objectives	1
1-3 Methodology	1
1.3.1 statistical Analysis	1
1-3-2 Data Sources	2
1-4 Organization of the study	2
2. Chapter two: Theoretical Analysis	3
2.1 Introduction	3
2-2 Concepts and Definitions	5
2-3 Disability & Poverty	8
2-4 Disability Dynamics	9
2-5 Disability & Education	9
2-6 Disability & Employment	10
2-7 Active Life Expectancy	10
2-8 Human Rights & Disability	10
3. Chapter Three: International Perspectives	12
3-1 Introduction	12
3-2 Role of International organization	12
3-3 Disability in the developing countries	14
4. Chapter Four: Disability in Sudan	16

4-1 Background	16
4-2 Population with Disability	16
4-3 Disability Differentials	19
4-3-1 Urban & Rural	19
4-3-2 Types of Disability	21
4-3-3 Causes of Disability	22
4-3-4 Gender & Disability	23
4-3-5 Age & Disability	24
5. Chapter Five: National Policies and Strategies	26
5-1 Policies	26
5-2 The Strategic Aim	26
5-3 The Objectives	26
5-4 Legislation	27
6. Chapter Six: Support Systems	29
6-1 Background	29
6-2 Support Systems in Sudan	30
6-2-1 Governmental Services	30
6-2-2 National NGO's	31
6-2-3 Foreign Support Programs	33
6-2-4 Khartoum Cheshire home	34
6-2-4-1 Background	34
6-2-4-2 The Medical Department	34
7. Chapter seven: Conclusion and Recommendations	37
References	40

# **List of Tables**

Table (3-1): Percentage of Persons with Disability by Area, Gender, and Age.	Page 14
Table (4-1): Disability Rates (per 1000) in Private Household by Sex and Mode of Living, According to States, Northern States, 1993	18
Table (4-2): Disability Rates (per 10000) by states and Type of Disability, Northern States, 1993.  Table (4-3): Percent of disabled persons according to Type of Disability among gender	20 21
Table (4-4): Percentage Distribution of Disabled Persons by Causes of Disability Types of Disability, Northern States, 1993.	22
Table (4-5): Disability Rates (per1000) by Gender and Type of Residence; Northern States, 1993.	23
Table (4-6): Percentage of Disability by Type of Disability, sex and Age group, Northern States, 1993	24
Table (4-7): Percentage of Disabled Population in Private Household by Causes of Disability, Sex and Age Group, Northern States, 1993	25
Table (5-1): Total numbers of Pension for works injury, 1975-2003	28
Table (6-1): Types of cases	35

## **Chapter One**

#### **Introduction**

#### 1-1 Background:

Understanding disability is an important step in ensuring that people with disabilities have the opportunities to participate fully in society. There are a large and growing number of persons with disability in the world to day. One major problem of studying the subject is to identify the population with disability. The complexity of the term has given rise to various definitions and indicators, and there is no accepted standard for counting the population with disability.

Poverty can greatly increase the chance of a person becoming disability, and a person with disabilities has a greater chance of experiencing poverty.

Equality of opportunities simply does not exist, where a disabled child cannot go to school, where a disabled mother has no health care, where disabled man cannot get training or job.

#### 1-2 Research Objectives:

- To define the different concepts of disability
- To study the demography of disability in Sudan according to Sudan National census of 1993 for Northern States.
- To shed light for support systems for people with disability in Sudan.
- To show the disability status in the world and the role of the international organizations.

#### 1-3 Methodology:

## 1-3-1 Statistical Analysis:

The basic analysis used is descriptive statistics, through the statistics tables and graphs, to analyze the Disability Differentials; through, urban & rural, types, causes, gender and age.

#### 1-3-2 Data Sources:

Five secondary sources of data are used:

- 1. Data on percentage of persons with disability by Area, Gender, and Age, obtained from UN Statistic Division-Disability statistic Version 2 (DISTAT-2).
- 2. Data on disability differentials (by states, resident, types, causes, gender and age); obtained from Central Bureau of Statistics (CBS) Analytical Report 1996, Population census 1993.
- 3. Data of disabled persons according to Type of Disability among gender obtained from National Center of Health Information, Sudan Maternal and Child Health Survey 1992/93.
- 4. Data on Total numbers of Pension for works injury obtained from National Social Insurance Fund, Department of Planning, Information and Statistics, December 2004.
- 5. Data on Total numbers Types of cases obtained from Khartoum Cheshire Home, Annual Report 2003.

## 1-4 organization of the study:

Chapter One: Introduction Including: Background, Research Objectives, Methodology (Statistical Analysis and Data Sources).

Chapter Two: show the Theoretical Analysis, this chapter studies the Concepts and Definitions of disability, Poverty, Dynamics, Education and Employment, Active Life Expectancy and Human Right of disability. Chapter Three: International perspectives: wherefrom role of International organizations and disability in the developing countries. Chapter Four: Study the demography disability in Sudan. There was study carried out as a census for disabled people according to Sudan National census of 1993 for Northern States. This chapter including: Disability Differentials; through, urban & rural, types, causes, gender and age. Chapter Five: This chapter attempts to study National Policies and Strategies for disabilities, through policies, strategic aim, the objectives and legislation in Sudan. Chapter Six: Highlight to the Support Systems in Sudan, through governmental services, National NGO's and foreign support programs; also we selected Khartoum Cheshire Home to study their activities (example for National NGO's). Chapter Seven: Conclusion and Recommendations

#### **Chapter two**

## **Theoretical Analysis**

#### 2-1 Introduction:-

There is a large and growing number of persons with disability in the world to day; more than 500 million people in the world are disabled as a consequence of mental, physical or sensory impairment. In most countries, at least one person out of 10 is disabled, and at least 25% of any population is adversely affected by the presence of disability. [UN 2003]

Much disability could be prevented through measures taken against malnutrition, environmental pollution, poor hygiene, inadequate prenatal and postnatal care, water-born diseases and accident of all types. The causes of impairments vary throughout the world as do the prevalence and consequences of disability. These variations are the result of different socioeconomic circumstances and of the different provisions that each society makes for the well-being of its members.

A survey carried out by experts has produced the estimate of at least 350 million disabled persons living in area where the services needed to assist them in overcoming their limitations are not available. To a large extent, disabled persons are exposed to physical, cultural and social barriers which handicap their lives even if rehabilitation assistance is available. Poverty and disability are closely intertwined and these two issues must be tackled together. An estimated 80% of the world's disabled people lives in the developing world and it is often noted that persons with disabilities are poor as a group than the general population, and that people living in poverty are more likely than others to be disabled. [UN 2003]

Equality of opportunity simply does not exist, where a disabled child cannot go to school, a disabled mother has no health care, a disabled man cannot get training or a job, or where disabled people cannot move freely on the street.

Many countries have taken important steps to eliminate or reduce barriers to full participation of the disabled. Legislation has in many cases been enacted to guarantee to disabled persons the right to, and opportunities for, schooling, employment and access to community facilities, to remove cultural and physical barriers and to proscribe discrimination against disabled persons.

There has been a movement away from institution to community —based living. In some developed and developing countries the emphasis in schooling is increasingly on "open education "with corresponding decrease in institution and special schools. Often, disabled persons have taken the lead in bringing about an improved understanding of the process of equalization of opportunities. In this context, they have advocated their own integration into the mainstream of society.

Persons with disabilities are entitled to the enjoyment of the full range of civil, cultural, economic, political and social rights embodied in international human rights instruments on an equal basis with other persons. Yet, the reality is different. In all societies of the world, including countries which have relatively high standard of living, person with disabilities often encounter discriminatory practices and impediments which prevent them from exercising fully in the activities of their societies.

#### 2-2 Concepts and Definitions:

One major problem of studying the subject is to identify the population with disability. The complexity of the term has given rise to various definitions and indicators, and there is no accepted standard for counting the population with disability.

There are several classification schemes for defining disability, but there is no good standard for measurement. Disability is not an attribute of an individual. Instead, disability exists when an individual's physical, cognitive or psychological capacity dos not fit the demands of a given task within a specific environment.

#### **Classic Medical Model:**

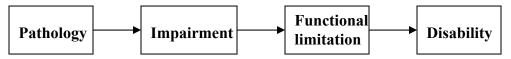
In the classic medical model, the characteristics of the person, rather than the environment, are salient in defining disability. Measures rooted in this model classify individuals according to the underlying biological or anatomical cause. [Vicki A. Freedman, Linda G martin, and Robert F.schoeni (2004)]

#### **Nagi's Functional Limitation Model:**

Depicts disability as a four-stage process: first, pathology, or compromised organ function due to chronic or acute conditions or injury; second, impairment, or the loss of system function; third, functional limitation, defined as limitations in physical or mental action due to the loss in system function; and finally, disability, or the inability to carry out socially defined roles or activities (see Figure 1). In this model, disability exists if the function loss is sufficient to restrict an individual from the performance of a socially defined role. [Vicki A. Freedman, Linda G martin, and Robert F.schoeni (2004)]

Figure 1:

#### **Nagi's Functional Limitation Model**



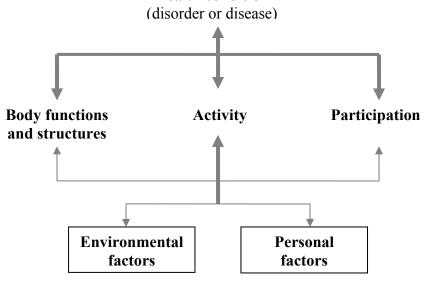
Source: Adapted from S.Z. Nagi, "Disability Concepts Revisited: Implication for Prevention," in Disability in America: Toward a National Agenda for Prevention, ed. A.M Pope and A.R. Tarlov (1991): 309-27.

# The International Classification of Functioning, Disabilities, and Health (ICF):

The original version of this system, the international classification of impairments, disabilities, and handicaps (ICIDH) adopted by (WHO) in 1980, recognized three stages: impairment, disability, and handicap. In this approach, disability is defined as limitation in activity; whereas handicap refers to the existence of a relative disadvantage compared to others because of the limitation (see Figure 2). The model makes explicit contextual factors-the individual's health condition, the environment, and other personal factors that may influence and interact with the process by which body function and structures relate to participation. [Vicki A. Freedman, Linda G martin, and Robert F.schoeni (2004)]

Figure 2:
International Classification of Functioning, Disabilities, and Health (ICF)

Health condition



Source: Adapted from World Health Organization (WHO), Towards a Common Language for Functioning, Disability, and health (2002):9.

The most commonly cited definition is that of the World Health Organization [WHO 1976], which draws a three-fold distinction between impairment, disability and handicap, as follows:

Impairment: is any loss or abnormality of psychological, physiological or anatomical structure or function.

Disability: is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Handicap: is a disadvantage for a given individual, resulting from an impairment or disability that prevents the fulfillment of a role that is considered normal (depending on age, sex and social and cultural factors) for that individual.

The Union of the Physically Impaired Against Segregation defined impairment and disability in the following manner: impairment is lacking of all of a limb, or having a defective limb, organism or mechanism of the body. Disability is the disadvantage or restriction of activity caused by contemporary organization which takes no or little account of people who have physical impairment and thus excludes them from the mainstream of social activities. [UPIAS 1976]

According to the United Nations Standard Rules on the equalization of opportunities for Persons with disability the term "Disability" summarizes a great number of different functional limitations occurring in any population in any country of the world. People maybe disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses maybe permanent or transitory in nature.

The term "Handicap" means the loss or limitation of opportunities to take part in life of the community on an equal level with other. It describes the encounter between the person with a disability and the environment, the purpose of this term is to emphasize the focus on the shortcoming in the environment and in any organized activities in society, for example information, communication and education which prevent a person with disability from participating on equal terms. [UN 2003]

Many factors are responsible for the rising number of disabled persons and the relation of disabled persons to the margin of the society.

These include:-

- War and the consequences of war and other forms of violence and destruction, poverty, hunger, epidemics and major shift in population.
- A high proportion of overburdened and impoverished families, and overcrowded and unhealthy housing and living conditions.
- Population with a high proportion of illiteracy and little awareness of basic social services or of health and education measures.
- An absence of accurate knowledge about disability, its causes, prevention and treatment. This include stigma, discrimination and misconceived ideas on disability.
- Inadequate programmers of primary health care and services.

- Constraints, including a lack of resources, geographical distance and physical and social barriers, that make it impossible for many people to take advantage of available services.
- The channeling of resources to highly specialized services that are not relevant to the needs help.
- The absence or weakness of an infrastructure of related for social assistance, health, education and vocational training.
- Low priority in social and economic development for activities related to equalization of opportunities, disability prevention and rehabilitation.
- Industrial, agricultural and transportation related accidents.
- Natural disasters.
- Pollution of the physical environment.
- Stress and other psycho-social problems associated with the transition from a traditional to a modern society.
- The imprudent use of medication, the misuse of therapeutic substances and the illicit uses of drug stimulants.
- The faulty treatment of injured persons at the time of a disaster, which can be the cause of avoidable disability.

## 2-3 Disability & Poverty:-

The relationship between poverty and disability has been established by numerous studies, but it is difficult to sort out the direction of the effect. The relationship may change over the life course, with childhood poverty increasing the risk of disability later in life, and disability in turn increasing the likelihood of poverty at middle and later ages.

Poverty can greatly increase the chance of a person becoming disabled, and a person with disabilities has a greater chance of experiencing poverty. There are many reasons why those who are living in poverty experience more disability than those who are not poor. Among these are: poor people may not have adequate food; they may live in unhealthy environments; they may have low-paying or dangerous jobs; they may be victims of violence; they have less access to medical treatment; they are less educated and therefore may not learn about treatment. Poor people lack access to information, influence and resources, which may cause them to live in poor living conditions and without proper medical care.

#### 2-4 Disability Dynamics:-

Disability depends on the health of an individual as well as the social and physical environment and the activities of interest. All of these factors can change frequently; therefore, the risk of having a disability is a highly dynamic phenomenon. The risk of disability not only changes over an individual's life course, but can also change from month to month or week to week.

At the population level, the extent of disability is affected by changes in the demographic composition of the population, medical discoveries in treatment and rehabilitation, technological innovation in support system, and behavioral risk factor for disease progression ( such as smoking, poor nutrition, lack of exercise, or poor adherence to medication regimens).

Most commonly used to description of disability dynamics at the population level include "disability prevalence" and "disability incidence." Disability prevalence is the proportion of the population at a given point in time that has a disability. In contrast, disability incidence is the proportion of the population (usually restricted to those who do not have disability) who develop disability within a given time frame. [Vicki A. Freedman, Linda G martin, and Robert F.schoeni (2004)]

## 2-5 Disability & Education:

At least 10 percent of children are disabled. They have the same right to education as non-disabled persons and they require active intervention and specialized services. But most disabled children in developing countries receive neither specialized services nor compulsory education. According to best estimates of international agencies, [UNESCO 2001] we know the following:

- ✓ 98% children with disabilities in developing countries do not attend schools.
- ✓ 500,000 children every year lose some of their vision due to vitamin A deficiency.

There is a great variation from some countries with a high educational level for disabled persons to countries where such facilities are limited or non existent. Significant advances in teaching techniques and important innovative development have taken place in the field of special education and much more can be achieved in the education of disabled persons. But the progress is mostly limited to a few countries or only a few urban centers.

#### 2-6 Disability & Employment:-

Many persons with disabilities are denied employment or given only menial and poorly remunerated jobs. In some industrialized countries experiencing the effects of economic recession, the rate of employment among disabled job-seekers is double that of able-bodied applicants for jobs. In many countries various programmers have been developed and measures taken to create jobs for disabled persons.

The actual number of disabled workers employed in either regular or special establishment is far below the number of employable disabled workers. The wider application of ergonomic principles leads to adaptation of the workplace, tools, machinery and equipment at a relatively little cost and helps widen employment opportunities for the disabled.

#### 2-7 Active Life Expectancy:

WHO has developed a useful model for thinking about population level linking among morbidity, disability, and mortality. The model depicts the proportion of a cohort that survives to a specific age without experiencing a particular event at the onset of disease, disablement, or death. Based on this framework, one can calculate summary information about disability and mortality into various averages and projections. Active life expectancy at birth for example, represents the average number of years lived from birth before the onset of disability. Active life expectancy at age 65 represents the average number of years lived after age 65 before the onset of disability. [Vicki A. Freedman, Linda G martin, and Robert F.schoeni (2004)]

#### 2-8 Human Rights & Disability:

In order to achieve the theme of the International Year of Disabled Persons," Full Participation and Equality" it is strongly urged that the United Nations System make all its facilities totally barrier-free, ensure that communication is fully available to sensorially impaired persons and adopt an affirmative action plan that includes administrative policies and practices to encourage the employment of disabled persons in the entire United Nations System. [UN 2003]

The rights-based approach to disabilities essentially means viewing persons with disabilities as subjects of law. Its final aim is to empower disabled persons, and ensure their active participation in political, economic, social and cultural life in a way that is respectful and accommodating of their difference. This approach is normatively based on International human rights standards and operationally directed to enhancing the promotion and protection of the human rights of persons with disabilities. Strengthening the protection of human rights is also a way to prevent disability.

Four core values of human rights laws are of particular importance in the context of disability:

- The dignity of each individual, who is deemed to be of inestimable value because of his/her inherent self-worth and not because she/he is economically or otherwise "useful";
- The concept of autonomy or self-determination, which is based on the presumption of a capacity for self-directed action and behavior, and requires that the person be placed at the center of all decisions affecting him/her;
- The inherent equality of all regardless of difference;
- And the ethic of solidarity, which requires society to sustain the freedom of the person with appropriate social supports.

## **Chapter Three**

## **International perspectives**

#### 3-1 Introduction:

The specialized agencies of the United Nations system which are involved in promoting supporting and carrying out field activities, have along record of work related to disability programmes of disability prevention, nutrition, hygiene, education of disabled children and adults, vocational training, job placement and other represent a store of experience and know-how which opens up opportunities for further accomplishment and at the same time, makes it possible to share these experiences with governmental and non-governmental organization concerned with disability matters.

#### 3-2 Role of International organizations:

The UN programme on disability is the lead programme on disability within he United Nations System, it is housed in the division for social policy and development at the department of economic and social affairs of the UN secretariat.

The mandate of the programme stems from the World Programme of Action concerning Disabled Persons adopted by the UN in 1982, which took place during the United Nations decade of disabled persons, there was a deepening of knowledge and extension of understanding concerning disability issues and the terminology used. And the Standard Rules on Equalization of Opportunities for persons with disability adopted in 1994.

The major objectives of the programme are the following: (i) to support the full and effective participation of persons with disability in social life and development. (ii) to advance the rights and protect the dignity of persons with disabilities, and (iii) to promote equal access to employment, education, information, goods and services. [UN 2003]

These organizations include:

o The concept adopted by the United Nations Children's Fund (UNICEF) of basic services for all children and the strategy adopted by it in 1980 to emphasize strengthening family and community resources to assist disabled children in their natural environment,

- o The United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA), which is concerned, among other things, with the prevention of impairments among Palestine refugees and the lowering of social and physical barriers which confront disabled members of the refugee population;
- o The office of the united nations high commissioner for refugees (UNHCR), with its programme for disabled refugees;
- o The office of the United Nations Disaster Relief coordinator (UNDRO); its concepts of specific measures of disaster preparedness and prevention of permanent disability as a result of injury or treatment received at the time of a disaster;
- o The United Nations Centre for Human Settlements (UNCHS), with its concern about physical barriers and general access to the physical environment;
- The United Nations Industrial Development Organization (UNIDO); the activities of UNIDO cover the production of drugs essential for the prevention of disability as well as of technical devices for the disabled.

#### Other International organization:

- o The basic needs strategy of the international Labour Organization (ILO) and the principles set forth in ILO concerning vocational rehabilitation of the disabled, in 1955;
- o The Food and Agriculture Organization of the United Nation (FAO), with its emphasis on the relation between nutrition and disability;
- o The concept of adapted education recommended by an expert group of the United Nations Educational, Scientific and Cultural Organization (UNESCO) on education of disabled persons;
- o The (WHO) programme of health for all by the year 2000 and the related primary health care approach, through which the member states of the (WHO) have already committed themselves to preventing diseases and impairments leading to disabilities.
- o The International Civil Aviation Organization (ICAO), which has approved recommendations to contracting states concerning facilities of movement and provision of facilities for disabled passengers;
- The Executive Committee of the Universal Postal Union (UPU), which has adopted a recommendation inviting all national postal administrations to improve access to their facilities for disabled persons.

#### 3-3 Disability in the developing countries:

The problems of disability in developing countries need to be specially highlighted. More than 80 percent of all disabled persons live in isolated rural areas in the developing countries. [UN 2003]

In some of these countries, the percentage of disabled population is estimated to be as high as 20 and thus, if families and relatives are included, 50% of the population could be adversely affected by disability. The problem is made more complex by the fact that, for the most part, disabled persons are also usually extremely poor people. In many countries, resources are not sufficient to detect and prevent disability and to meet the need for the rehabilitation and supportive services of the disability population.

To explain this result we have data published from the UN Disability statistics database, which studies the number of persons with disabilities, and we selected countries duration 1990-1994 for which data is available. [UN Statistic Division2003]

Table (3-1)

Percentage of Persons with Disability by Area, Gender, and Age.

Country	Total	Ar	ea	Gender			Age	
		urban	rural	male	female	0-14	15-59	65+
Peru 1993	1.3	1.2	1.6	1.3	1.3	0.7	1.2	5.3
Syrian 1993	0.8	0.8	0.9	1.0	0.6	0.6	0.9	1.9
Brazil 1991	0.9	0.9	0.9	1.1	0.7	0.4	0.9	2.7
Nigeria 1991	0.5	0.4	0.5	0.5	0.5	0.3	0.5	1.2
Zambia 1990	0.9	0.7	1.1	1.0	0.9	0.6	1.0	3.4
Yemen 1994	0.5	0.5	0.5	0.6	0.5	0.1	0.7	3.0

Source: UN Statistic Division2003-Disability statistic Version 2 (DISTAT-2).

Table (3-1) shows some of the developing countries that have 0.5% and more in total of persons with disability. In this table we find the disabled people in rural more than urban, maybe for civil war, not have access to basic services including rehabilitation facilities, primary health care, etc... We find the percentage among male high than female probably due to grater risk of accidents among male. In most countries the number of elderly people is increasing, and already in some as many as two thirds of disabled people are also elderly, we see this in percentage among group 65+ is highest than group 0-14 and 15-56.

In such countries, the disability problem is further compounded by the population explosion; which inexorably pushes up the number of disabled persons in both proportional and absolute terms. There is thus, an urgent need, as the first priority, to help such countries to develop demographic policies to prevent an increase in the disabled population and rehabilitate and provide services to the already disabled.

For many women and children, the person of an impairment leads to rejection or isolation from experiences that are part of normal development.

There are over 10 million refugees and displaced persons in the world today as the result of man-mad disaster many of them are disabled physically and psychdogically as a result of their sufferings from persecution, violence and hazards. Most are in third-world countries, where services and facilities are extremely limited. Being refugees is in itself a handicap and a disabled refugee is doubly handicapped.

## **Chapter Four**

## **Disability in Sudan**

#### 4-1 Background:

As a result of the civil war and the harsh economic circumstances, the total a mount of disabled people in the Sudan has increased and disability seems to gradually become a bigger issue in the health condition of the Sudanese people.

For children, physical disability is inflicted by many diseases and other causes, but major causes are still poliomyelitis and cerebral palsy. Polio immunization remained less than 20% until a national polio eradication programme was launched in 1997

Also cerebral palsy is still a major problem in Sudan as a result lack of proper antenatal care and high prevalence of meningitis and convulsions. Estimated 1 out of every 300 babies born has or will develop cerebral palsy. [Ridda Ali S.1997]

The United Nations estimated that in the period of 1985-1993, 5.3% of the population was disabled, this including the mentally disabled, the deaf and dumb, the blind, the physically disabled, persons with multiple disabilities and persons with other disabilities.

As the needs of services to the disabled remarkably increased, the government encouraged the non-governmental organizations working in the filed of disability to provide services for disabled persons. But unfortunately there has been little up-to date information or about supportive services provided about disability.

#### 4-2 Population with Disability:

Defining size of disability among population, and knowing the kind of disability and its reasons, are of the most important matters which health policy makers and human development policy makers should bear in mind because the disabled are considered unemployed energies if care, education and rehabilitation opportunities are not available for them, to integrate them in society, and their active participation in the social and economic development process.

In Sudan, there was study carried out as a census for disabled people according to Sudan National census of 1993 for Northern States, this is the first time that a question was asked on disability in a census in Sudan. In the census a question was asked whether there was any one with disability in the household and the disabilities were spelled out. The disabilities covered by this census included the following type of disability:

- Physically disabled
- Deaf and Dumb
- Blind
- Combined
- Mentally Retarded
- Other

According to the 1993 census, nearly 337610 people or almost 1.59% of the population having disability. [Jaffar M Saeed, 1996]

Table 4-1 show the disability rate among different states of the Northern Sudan for both sexes, 13.3 per 1000 for urban areas and 17.1 per 1000 for rural areas. Also the Table shows that disability rates per thousand among males are higher than females. 17.8 per 1000 of total male population are disabled, while the rate is 14.0 per 1000 for females.

Table 4-1

Disability Rates (per 1000) in Private Household by Sex and Mode of Living, According to States, Northern States, 1993

STATES		TOTA	L		URBA	N		RURAL	ı
	Both	Male	Female	Both	Male	Female	Both	Male	Female
	sexes			sexes			sexes		
Northern States	15.9	17.8	13.9	13.3	14.8	11.7	17.1	19.2	15.0
Northern	17.9	21.4	14.7	10.6	12.7	8.4	19.0	22.8	15.6
Nuhr-al-Nil	16.8	21.1	12.7	13.3	15.9	10.8	18.2	23.4	13.4
Red Sea	11.1	12.0	10.2	11.7	12.8	10.4	10.5	11.1	10.0
Kassala	12.3	14.8	9.7	11.7	13.4	9.9	12.5	15.4	9.6
<b>AL-Gadarif</b>	13.4	15.1	11.4	12.9	14.9	10.7	13.5	15.2	11.7
Khartoum	11.6	13.4	9.5	11.5	13.4	9.4	11.8	13.7	9.8
Al-Gezira	15.2	18.2	12.3	12.8	15.0	10.5	15.7	19.0	12.6
Sinnar	16.1	20.1	12.1	13.9	16.0	11.8	16.7	21.5	12.2
White Nile	17.7	20.7	14.9	14.2	16.0	12.5	19.5	23.1	16.1
Blue Nile	12.5	13.6	11.3	13.9	14.8	12.8	12.1	13.3	11.0
Northern Kordufan	18.2	20.5	16.0	14.9	16.9	13.0	19.2	21.6	17.0
Western Kordufan	16.3	17.8	14.8	17.1	17.3	16.8	16.2	17.9	14.5
Southern Kordufan	18.9	20.8	17.1	17.8	19.9	15.8	19.1	21.0	17.3
Northern Darfur	22.8	23.0	22.6	17.4	17.3	17.6	23.8	24.2	23.5
Western Darfur	20.1	21.0	19.3	29.5	26.1	32.7	19.1	20.5	17.8
Southern Darfur	18.2	18.6	17.7	18.1	18.3	17.8	18.2	<b>18.7</b>	17.7

Source: Central Bureau of Statistics (CBS) Analytical Report 1996, Population census 1993.

#### **4-3 Disability Differentials:**

#### 4-3-1 *Urban & Rural*:

The disability rates in the rural areas are higher compared to those of urban areas. This true in all states except Blue Nile, Western Kordufan, and Red Sea states where the rates for rural are lower than the urban. For example the rate for Blue Nile are 13.9 for urban and 12.1per thousand for rural (Table 4-1). The reason of this is that because of medical care and social education of disabled in addition to the struggle against negligent of mother and child health, also the disabled people live in this areas have low-income; so the majority of them are poor and do not have access to basic services etc...

Figure 4-1:

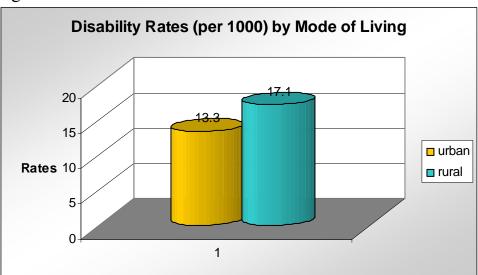


Table 4-2 Disability Rates (per 10000) by states and Type of Disability, Northern States, 1993.

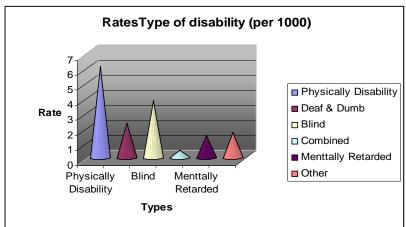
STATE	ALL	TYPE OF DISABILITY					
	DISABILITY	Physically	Deaf &Dumb	Blind	Combined	Mentally Retarded	other
Sudan-Northern States	15.9	6.1	2.3	3.8	0.5	1.5	1.7
Northern state	17.9	5.6	2.5	3.6	0.5	2.8	2.8
Nahr-El- Nile	16.8	6.6	2.7	3.3	0.5	2.4	1.4
Red sea	11.1	3.3	1.6	2.1	0.4	1.6	2.1
Kassala	12.3	4.2	1.4	3.3	0.3	1.5	1.5
Al Gadarif	13.4	4.9	2.2	3.3	0.4	1.3	1.2
Khartoum	11.6	5.1	1.9	1.9	0.3	1.1	1.3
Al Gazira	15.2	6.4	2.4	3.4	0.4	1.2	1.4
Sinnar	16.1	5.3	2.3	4.8	0.8	1.4	1.6
Whit Nile	17.7	6.4	2.4	4.1	0.9	1.6	2.2
Blue Nile	12.5	4.5	1.7	3.9	0.5	1.0	1.0
Northern Kordufan	18.2	6.7	2.9	4.7	0.6	1.4	1.8
Western Kordufan	16.3	6.1	2.8	3.9	0.4	1.8	1.3
Southern Kordufan	18.9	7.9	2.9	4.4	0.5	1.7	1.6
Northern Darfur	22.8	8.2	2.8	5.5	1.0	2.5	2.7
Western Darfur	20.1	7.9	2.5	5.4	0.5	2.0	1.6
<b>Southern Darfur</b>	18.2	6.69	2.3	5.2	0.5	1.6	1.9

Source: Central Bureau of Statistics (CBS) Analytical Report 1996, Population census, 1993. Final tabulations Vol 2 table S 11.

#### 4-3-2 Types of Disability:

Table 4-2 shows that physical disability rate is 1.6 per 1000 of total population that is the highest rate compared for the remaining type of disability. The second highest is the rate for blind 3.5 per 1000. (Table 4-2) explain the rates for physical disability and blind are high for the different states, Northern Darfur, Western Darfur, Southern Kordufan have the highest physically disability rates 8.2, 7.9, 7.9 per 1000 respectively. The reason of this is that because war, mines, accident and polio that due to lack of vaccination in that time. Also the Northern Darfur, Western Darfur, Southern Darfur has the highest blind rates 5.5, 5.4, and 5.2 per 1000 respectively.

Figure 4-2



The National center of Health Information (Maternal and Child Health) Survey estimates that the most prevalent kind of disability among males and females were blind disability followed by physically and deaf disability (See Table 4-3), they are 23.2% Blindness among male, and 24.3% among female.17.2% of the physically among male, and 19.1% among female. [National Center of Health Information, Sudan – Maternal and Child Health Survey 1992/93.]

Table 4-3
Percent of disabled persons according to Type of Disability among gender

<b>GENDER</b>		TYPES OF DISABILITY							
	Blind	ind Deaf Physically Mentally Other Not No							
		&Dumb		Retarded		stated	Disability		
Male	23.2	16.7	17.2	7.5	15.7	19.7	228		
Female	24.3	17.3	19.1	8.1	12.7	18.5	173		

Source: National Center of Health Information, Sudan – Maternal and Child Health Survey 1992/93.

#### 4-3-3 Causes of disability:

In the 1993 Census, 61.2% of all disabilities are caused by disease and Acquired cause comes next with 17.7%. If we consider the causes of each type of disability separately, 62.8% of physical disability and 71.1% of blindness are caused by disease, which means there is no health care for children and mothers (Table 4-4). 22.4% of physical disability, and 17.7% of combined are caused by Acquired Accident.

Table 4-4

Percentage Distribution of Disabled Persons by Causes of disability Types of Disability, Northern States, 1993.

Causes of	All	Physical	Deaf &	Blind	Combined	Mentally	Others
Disability	<b>Types</b>		Dumb			Retarded	
All	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Causes							
Inherited	9.5	6.4	16.4	6.4	11.5	21.5	6.7
Acquired	17.7	22.4	16.7	14.3	17.7	16.3	14.7
Accident							
Disease	61.2	62.8	50.8	71.1	57.4	49.9	54.5
Others	11.6	8.4	16.1	8.2	13.4	12.3	24.1

Source: Central Bureau of Statistics (CBS) Analytical Report 1996 Population Census 1993; Final tabulation, VOL2 Table S 14.

Percentage of Disabled Persons by Causes of
Disability

11.6 9.5
17.7
| Innherited
Acquuired Accident
Disease
Others

Figure 4-3

#### 4-3-4 Gender and Disability:

17.8per 1000 disability rate among males, and 13.9 per1000 among female according to the 1993 Census, in most states the disability rates for male is grater than the disability rates among female, (see Table 4-1) probably due to grater violence, accidents, work related, war injuries, etc... 14.8per1000 disability rate for male among urban areas and 19.2per1000 among rural. 11.6per1000 disability rate for females among urban areas and 15.1per1000 among rural. (Table 4-5). This result has proved that disability in urban areas is less than rural areas.

Table 4-5 Disability Rates (per1000) by Gender and Type of Residence; Northern States, 1993.

TYPE OF		<b>MALES</b>			<b>FEMALES</b>	
RESIDENT	Total population	Total Disabled	Disability Rate	Total population	Total Disabled	Disability Rate
	(000)	(000)		(000)	(000)	
Total	10,671	189	17.8	10,595	148	13.9
URBAN	3,565	53	14.8	3,264	38	11.6
RURAL	7,106	136	19.2	7,330	110	15.1

Source: Central Bureau of Statistics (CBS) Analytical Report 1996 Population Census 1993; Final tabulation, VOL2 Table S 11.

Disability Rate (per 1000) By Gender 20 <del>13.9</del> 15 male Rates 10 □ female 5 1 Gender

Figure 4-4

#### 4-3-5 Age and Disability:

According to the 1993 Census, the prevalence of disability increases with age. 22.7% disability among male, and 26.9% disability among female in age group 65or older. Table 4-6 shows the percentage distribution of disabled persons by age groups in different type of disability and gender. It is observed that disability percentage among elderly (65 or older) blindness is the most prevalent type of disability for males and females (53.3%, 32.7%) respectively.

Table 4-6

Percentage of Disability by Type of Disability, sex and Age group,
Northern States, 1993

		- 10-		,			
SEX	TYPE OF						
	DISABILITY	0-4	5-14	15-24	25-44	45-64	65+
Male	All Types	3.9	15.7	15.3	22.6	19.8	22.7
	Physical	4.8	16.2	16.0	24.8	21.2	17.0
	Deaf& Dumb	5.9	25.9	20.4	21.4	15.6	10.8
	Blind	1.7	6.2	5.6	3.6	29.6	53.3
	Combined	6.1	7.0	7.4	50.1	7.4	22.0
	Mentally	2.4	23.2	26.5	31.4	11.9	4.6
	Others	4.3	13.2	15.0	28.0	23.3	16.2
Female	All Types	4.3	14.6	11.9	20.8	21.2	26.9
	Physical	5.2	5.6	6.7	56.1	6.6	19.8
	Deaf& Dumb	8.2	4.6	20.2	24.3	29.3	13.4
	Blind	1.5	2.3	3.6	31.6	28.3	32.7
	Combined	1.6	5.9	7.2	5.7	47.4	32.2
	Mentally	3.8	12.2	20.2	20.0	36.1	7.7
	Others	3.3	11.7	12.7	29.8	22.6	19.9

Source: Central Bureau of Statistics (CBS) Analytical Report 1996 Population Census 1993; Final tabulation, VOL2 Table S 12.

Regarding males for age groups less than 4 years the most prevalent type of disability is combined, where the most prevalent type among females for group under 4 years is Deaf and Dumb.

Causes of disability varied according to age groups (Table 4-7). In age group 5 to 14 the most important causes of disability are Inherited for both sexes, which have 26.6% among male, and 27.5% among female.

Also 1993 Census shows that the Acquired Accident causes in 25 to 44 years are high percent more than another cause for both sexes, which have 24.4% among male, and 20.6% among female.

Up to 65 years, diseases are the main causes of disability for each sex, which have 27.4% for male, and 31.3% for female.

Table 4-7

# Percentage of Disabled Population in Private Household by Causes of Disability, Sex and Age Group, Northern States, 1993

Source: Central Bureau of Statistics (CBS) Analytical Report 1996 Population Census 1993; Final tabulation, VOL2 Table S 13.

SEX	CAUSES OF DISABILITY	0-4	5-14	15-24	25-44	45-64	65+
Male	All Causes	3.9	15.7	15.3	22.6	19.8	22.7
	Inherited	6.3	26.6	22.1	26.1	12.4	6.5
	Acquired	2.8	16.1	17.2	24.4	19.8	19.9
	Accident						
	Disease	3.0	13.1	13.6	1.0	21.9	27.4
	Others	8.8	20.7	14.8	23.7	14.9	17.1
Female	All Causes	4.3	14.6	11.9	20.8	21.2	26.9
	Inherited	7.4	27.5	18.8	26.5	14.2	5.6
	Acquired	4.3	15.9	13.8	20.6	20.5	24.9
	Accident						
	Disease	2.9	11.4	10.2	20.5	23.7	31.3
	Others	8.9	18.9	13.6	18.8	15.5	24.3

## **Chapter Five**

## **National Policies and Strategies**

#### 5-1 Policies:

- ➤ To be as a commitment spiritual, social values as well as the folklore of Sudanese nation in rehabilitation and integration handicaps people in the society and this will make them as participants in the development.
- ➤ Rising to the standard of disabled people in social, health, cultural, academic, vocational and athletics in different cultural and needs.
- ➤ Utilization from modern technology in the training and rehabilitation disabled people and their staff.
- ➤ Proceeding many studies and researches on the disability problem and highlight on this stratum.
- ➤ Benefiting from the regional and international experiences in this field.

## 5-2 The Strategic Aim:

By planning and coordination and spreading the disability services and working for their rehabilitation to realization the social integration which reaching into social equity.

#### 5-3 The Objectives:

- To reinforce the society and family role and approving the rehabilitation schemes which based on family and society for realizing better services with less cost.
- To let disabled person to be self-dependent and combine them with society.
- To provide educational services, health, pedagogical and rehabilitation to be care for disabled people.
- Put into consideration the actual work opportunities in environment and knowing the work which are available in the local environment.
- Directing the possibilities and local sources for the benefit of disabled people.
- Raising the standard of the training programme for the different groups of workers in this filed and designing programme that by providing comprehensive information on the prevention from disability and rehabilitation.

- To focus on handicaps protection and support their families, because that it is considerd to be the care for the generation welfare and upbinging.
- To focus on the important the regional and international cooperation in the field of the disabled people as a tool for consolidation and planning and work programme with this group.
- To activate the national council for welfare and rehabilitation of disabled people and establishing the regional councils.

[Ministry of Social Welfare and Human Development1998]

#### 5-4 Legislation:

Legislation is an important mean to realize their aims. In 1990 the Social Insurance Act was issued replacing 1974 Act, and amended in 2004. **Section 42**: the provisions of work injuries pension insurance shall apply to the insured persons, who as a result of work injury, sustain a permanent disability of 15% or more, or die as a result or the injury. The obligation of the Fund shall arise after proof of the disability, or after death.

**Section 44:** Where a permanent total disability arises out of the injury, the Fund shall pay, to the inured person, a monthly pension equal to 80% of the average of his monthly wages of the last year, at the time of proof of disability.

**Section 45:** The Fund shall pay the insured person, where he sustains a partial disability assessed at 15% or more, and a monthly pension equal to the assessed percentage of such disability, from the permanent total disability pension, provided for in section 44.

Also the Works Injuries Act 1981 regulates matters of works Injuries and the percentage of disability together with the necessary compensation. Table 5-1 shows the statistics numbers of cases where pension is afforded for works injury. [National Social Insurance Fund; the Work Injuries Act 1990 amended in 2004]

Table 5-1

Total numbers of Pension for works injury 1975-2003

Year	Death	Total	Partial	Total
		Disability	Disability	
75-76	9	-	7	16
76-77	12	1	24	36
77-78	25	5	86	116
78-79	23	4	206	233
79-80	39	11	328	378
80-81	13	-	251	264
81-82	30	-	236	256
82-83	29	1	153	183
83-84	28	4	188	220
84-85	24	2	163	189
85-86	30	-	93	123
86-87	33	2	131	166
87-88	24	2	60	86
88-89	15	-	48	63
89-90	7	1	87	95
90-91	28	1	20	49
91-92	40	-	74	114
92-93	21	-	66	87
93-94	23	2	89	114
94-95	39	-	81	120
Transition	3	-	60	63
period 95				
1996	18	1	98	116
1997	23	1	120	144
1998	25	-	84	109
1999	63	9	158	230
2000	51	1	175	227
2001	63	4	267	334
2002	43	7	224	274
2003	42	5	183	230
Total	823	63	376	1262

Sources: National Social Insurance Fund, Department of Planning, Information and Statistics, December 2004.

# **Chapter Six**

# **Support Systems**

## 6-1 Background:

Support systems for people with disability include personal care services, technological assistance, and other strategies employed to accomplish daily tasks. These systems, whether at home or in group setting, make it possible for people with disability to carry out their world, and participate as citizens.

Such services and strategies are made available through a patchwork of public and private providers and programs.

#### **Personal Assistance:**

Personal assistance, also called "personal care" or "personal assistance services" refers to hands-on, standby, or supervisory help provided to people of any age. Personal assistance services for people with disabilities may be provided in the community (some time called community –based long-term care services) or in group or institutional settings.

Relatives most often adult children and spouses make up the majority if informal caregivers to adults. The overwhelming majority of children with mental retardation and developmental disabilities who live in the community do so with one or both parents.

# **Technological Assistance:**

Technology is becoming increasingly important in the lives of people with disabilities. Some technologies- such as automatic teller machines, direct deposit, and shopping online were no originally designed to overcome disabilities. Other technologies are used to bridge the gap between an individual's capacity and the demands of his or her environment. Such technologies include: mobility devices such as walkers, canes, and wheelchairs; bathing devices such as shower stools; and adaptations to care, computers, and telephones that assist people with disabilities in carrying out their day-to-day activities. [Vicki A. Freedman, Linda G martin, and Robert F.schoeni (2004)]

# 6-2 Support Systems in Sudan

The first service for disabled people was established in 1960 by setting up Elnur Institute for the education of the blind. In 1966 this service became one of the concerns of the unit of General Assistance attached to the Department of social care. This was further developed into specialist directorates that cater for the needs of the disabled. Now the Ministry of Social Planning concerns itself greatly with the different groups of the disabled, this being a part of its objectives and policies in the wider context of the comprehensive national strategy.

The Care and Rehabilitation of the Disabled Act was issued in 1984. According to this Act, the National Council for the custody and rehabilitation of the disabled was established under the auspices of the particular minister to draw the policies relevant to the custody and rehabilitation of the disabled at a national level. In this chapter, we will try to shed light on different services provided by government and non-government organization [The National Center for Artificial Limb1996]

#### 6-2-1 Governmental services:

There are a number of governmental institutions which provide services to disabled persons: Elnur Institution for the academic education of the blind at the basic level (girls & boys), located at Khartoum North. It was established in 1960.

- Elsalamabi Institute for listening and communication for education of the Deaf and Dumb and the difficult of hearing for children. For (boys & girls) located at Khartoum. It was established in 1989.
- The National Center for Artificial Limbs; it started as a unit in the Sudan Defence Force in 1946 to manufacture the artificial limbs for the military persons injured in the World War II. A year later it was attached to Mechanical Transportation Department up to 1974, and in 1993 it was attached to the Ministry of social planning, according to a decree from the council of Ministers. It started by imitating the limbs manufactured in England and later developed to manufacture equipment for paralysis and supportive splints and the treatment of the spine.

In 1989 a trilateral agreement was signed between the social care, (Now the Ministry of Social Planning), The Ministry of Defence and the Red Cross. The agreement specified the role of each part. The Red Cross was to provide the raw materials and the other imported equipment and the training experts. The Social Care and the Ministry of Defence provide the local materials in addition to the salaries and wages of the personal; military and civil. A very ambitious plan was

- drawn with clearly defined stages for the betterment of performance and the progress of the services in addition to the promotion of the working conditions of the employees.
- The comprehensive Production Factory for the disabled in (East-Khartoum) was established in 1991 in collaboration with the Islamic rehabilitation Agency (IRA) and UNDP and the government of Sudan for the employment of the disabled (male &female) in a number of crafts.

### 6-2-2 National NGO's:

It is considered not only complementary to the governmental efforts but also prior to it, which indicates the voluntary awareness to wards the disabled. According to Sudan Council of Voluntary Agencies (SCOVA) there are a number of national NGO's which have activities related to disabled people.

- Elamal Institute (Sudanese National Association of Deaf & Mutes Welfare) for the education of the Deaf children which is apart of the national society for the care of the Deaf. It was established in 1973 by D. Taha Talat, it has ten branches in Khartoum, Khartoum north, Omdurman, Al-Gadarif, Medani, Port-Sudan, Kassala, Al-Abaid, wau and Juba.
- Elafaq Elawsa (Wider Horizons Society), located in Atbra offers educational, rehabilitation and custody services for the mentally disabled.
- Sakeena Institute established in 1985, for the mentally disabled, located in Omdurman. Their aim offers medical, educational and rehabilitation services.
- Cheshire Home which is a rehabilitation center for children with a physical disability. It was established in 1974, and located in Khartoum.
- Elrajaf Institute which offers educational and vocational rehabilitation to the blind (Juba).
- Sudanese National Association of the Blind, established in 2000, which has branches in most of Sudan States, (River Nile, Port Sudan, Kassala, Gadarif, Gezira, White Nile, Bahr El Jubal, Kordofan and Darfur). Its objectives are developing of blind person educationally, culturally, socially and prevention of blindness among the targets, integration of blind in the society, find employment opportunities for the blind, participation in public ceremonies.

- Sudanese Association for Rehabilitation of Handicapped, its location in Khartoum north, which has branches in all states; their objectives are the Care and rehabilitation of handicapped.
- Abrar Association for Care of War Disabled and protection from Land Mines; its location in Khartoum, its objectives are for peace building, mines combat, training and rehabilitation of war affected people. It's established in 1997.
- National Association of Deaf & Mutes; in Khartoum North. Its objectives are Care and rehabilitation of Deaf and mutes, awareness rising and training.
- Sudanese Association for the mentally Retarded Children, in Khartoum.
   Its objectives are the rehabilitation of mentally handicapped children.
- El-Anees Center for Speaking and language is established on 2002, in Khartoum, for Children with special needs.
- Sudanese Center for rehabilitation of children with special needs, it provided its services in 1996, in Omdurman.
- Frsan El Erada center for the children with special needs. Its location in Khartoum (3), and established in 1995.
- Ahbab Allah (Allah's beloved) Center for servicing children with special needs Khartoum.
- Asratna Association for Disabled Children (Khartoum), which has established in 1999.
- Basma Society for the mental development Khartoum in 1990. [Sudan Council of Voluntary Agencies (SCOVA) 2003]
  - ❖ We have tried to contact some of these National NGO's to study their activities, but we failed to get any useful information.

    The only organization which was cooperative was Khartoum Cheshire Home, which we will address in more details in section 6-2-4.

# 6-2-3 Foreign support programs:

- O Community-Based Rehabilitation (CBR): the objectives behind this programme is to develop effective measures for the rehabilitation and achievement of participation and equality for the disabled in addition to the utilization of the local resources in the field of vocational rehabilitation as far as the training, employment and profits are concerned. The programme started in 1991 in Co-operation with UNDP and ILO. In its fist phase it covered 6 of the Sudan States.
- Association of Disabled Development: its a British organization which offers support to all of the disabled groups, in all areas to training, financing the individual and group project to all the disabled.
- Norwegian Organization for Disability in Juba,0 their objectives is care and development of disabled persons.
- o Nile Assistance to the Disabled (NAD), provided its services to the physically disabled at Juba, where it created a workshop to the artificial limbs. In addition it manufactured sticks and wheelchairs, its established in 1984.
- o Action on Disability and Development (ADD). It is one of the few British-based organizations supporting right based development work, exclusively with groups of disabled people in Africa and Asia. Aimed to help the disabled societies and association and the disabled individuals to achieve their programmes and projects. Established in 1984, where located in Khartoum. The organization cooperate with some association and societies at Khartoum, Nyala, Madani, Gadarif and Kassala by creation of training workshop for the cadres, workshops for Artificial Links and wheel chairs and small productive projects. [Sudan Council of Voluntary Agencies (SCOVA) 2003]

### 6-2-4 KHARTOUM CHESHIRE HOME

## 6-2-4-1 Background:

Khartoum Cheshire Home (KCH) was founded in 1974 by Leonard Cheshire International, Great Britain.

The home is well recognized and legally registered as an NGO with the Ministry of social planning, Humanitarian Affairs Commission, (HAC) and Humanitarian Voluntary works, and the other NGO's working in Sudan.

It's working in close cooperation with several others NGO's, Christoffel Blindn Missions (CBM), Leonard Cheshire Foundation International, UNICEF, the Leprosy Mission (TLM), Action and Disability and Development (ADD), German Development Organization (DED) and others.

(KCH) has being working as the organization in Sudan that treats and provides the services for the handicapped children between 0 to 16 years; including physiotherapy, skills training, school, surgery and mobility aids, speech therapy, hydrotherapy, clinics, community based rehabilitation, social activities, etc...

For the past 30 years it has treated more than 12000 handicapped children from all over Sudan have received support from the Home. It's provides this support free of charge and is entirely reliant on voluntary donations.

Total number of staff is 58 including all medical and supporting staff. There are two main departments at KCH in –patients and out-patient. More than 50 children can be lodged at the Home when recommended by our volunteer doctors.

(KCH) is collaborating with the Broader Horizon institute (BHI) in Atbara Sudan North, an organization helping children with special needs, and the Western Sudan Union of the disabled via the Leprosy Mission, Western Darfour, refers children to (KCH) for treatment and operations.

# 6-2-4-2 The Medical Department:

The medical department covers two areas: the clinic and the surgery.

# **Surgery:**

In 2003 they are 278 operations were conducted.

#### Clinics:

A team of volunteer doctors hold three clinics per week. The team consists of an orthopedic surgeon, a pediatrician and consultant in physical medicine. the type of cases seen: Cerebral Palsy 70%, polio 14%, Clubfeet 7%, Erbs Palsy 2% and Other (muscular myopathy, spinabifida, congenital conditions) 7%.

The KCH working with other disabilities, 200 children with hearing impairment and 99 children with visual impairment were referred to the respective specialize institutions for treatment and care.

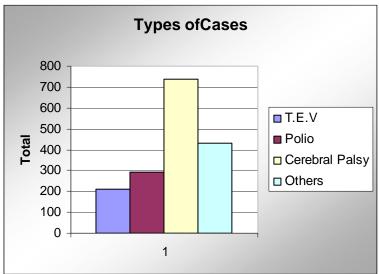
In year 2003, 1671 cases were seen. Cerebral Palsy has the highest number among other cases. (Table 6-1)

Table 6-1

Types of cases	
CASES	NUMBER
T.E.V	213
Polio	291
Cerebral Palsy	737
Others	430
Total	1671

Source: Khartoum Cheshire Home. Annual Report 2003

Figure 6-1



# Orthopedic workshop:

Many of the children who came to the Home need walking aids or other orthopedic equipment. Simple, strong and light devices are made in our workshops using locally available materials. During 2003 over 5149 aids were given to children, including braces, crutches, walking frames, special seats and wheelchairs.

## **Operating Theatre**:

Due to the increasing number of children waiting for operations and the shortage of beds at the hospital an operating theatre has recently been built within the Home. Orthopedic surgeons can carry out up to 300 operations a year on the children.

#### Our school:

The school for in-patients opened its door in 1998, children who have been admitted receive basic schooling, and 95% of them never went to school before. The idea is to get them re-integrated in the regular school system once back home. The teachers who is handicapped herself, is doing a great job by using active teaching techniques (singing, drawing, physical education, theatre, etc...). They divided up the children in groups according to their level.

## Donors for the year 2003:

- ➤ **CBM** is the main donor covering 75% of last year budget
- ➤ UNICEF: Supported KCH with SD1, 924,800 to carry out community awareness and training of field workers for the outreach programme.
- ➤ Lillian Found: Supported KCH with SD807, 662.00 for educational support and medications to the children with disabilities.
- ➤ War Child: Supported social & cultural activities for inpatients.
- > KCH also received collection from the fundraising, individuals and friends
- ➤ **Kenana Sugar Co.** supported KCH running cost-SD1, 500,000.00 [Khartoum Cheshire Home Annual Report 2003]

# **Chapter Seven**

# **Conclusion and Recommendations**

- \*The United Nations determined the percentage of disability by 7%-10% in the world population, this percentage increases to 14% in the cases of war, poor primary health care and disasters, which means that there may be more than 500 million people with special needs. The majority, an estimated 80%, live in developing countries.
- \*Poverty can greatly increase the chance of a person becoming disability, and a person with disabilities has a greater chance of experiencing poverty.
- \*Most disabled children in developing countries receive neither specialized services nor compulsory education.
- \*Many persons with disabilities are denied employment or given only menial and poorly remunerated jobs.
- \*In Sudan, there was study carried out as a census for disabled people according to the population census 1993, show that almost 1.59% of the population having disability.

From the analysis of the demography of disability in Sudan, we found that:

- \* Disability rates per thousand among males are higher than females.
- \*The disability rates in the rural areas are higher compared to those of urban areas.
- \*Also shows that physical disability rate is 1.6 per 1000 of total population that is the highest rate compared for the remaining type of disability.
- \*Northern Darfur, Western Darfur, Southern Kordufan have the highest physically disability rates 8.2, 7.9, 7.9 per 1000 respectively.
- \*In the 1993 Census, 61.2% of all disabilities are caused by disease and Acquired cause comes next with 17.7%.

* Also the prevalence of disability increases with age. 22.7% disability among male, and 26.9% disability among female in age group 65or older. And in this age group diseases are the main causes for each sex, which have 27.4% for male, and 31.3% for female.
To round our discussion off, one can make the following

recommendation;

- A. Should ensure the presentation of systematic information about the realities of disability and its consequences and about prevention, rehabilitation and the equalization of opportunities for disabled persons.
- B. For reducing the incidence of impairment and disability, and the most important measures for prevention of disability are:

  Identification of types of disability and their causes within defined geographical areas; improvement of health services, early detection and diagnosis; prenatal and postnatal care; proper health care instruction, including patient and physician education; family planning; legislation and regulations; modification of life-styles; selective placement services.
- C. Rehabilitation usually includes the following types of services: Social, psychological and other types of counseling and assistance; training in self-care activities, including mobility, communication and daily living skills, with special provisions as needed; specialized education services; vocational rehabilitation services, vocational training, placement in open sheltered employment. Especially in rural areas, that have high rate of disability.
- D. Disabled person should have element of living, including family life, education, employment, housing, financial and personal security, participation in social and political groups, religious activity, intimate and sexual relationships, access to public facilities, freedom of movement and the general style of daily living.
- E. Should establish and development of a public system of social care and industrial safety and health protection.
- F. Should adopt a policy and supporting structure of services to ensure that disabled persons in both urban and rural areas have equal opportunities for productive and gainful employment in the open labour market. Rural employment and the development of appropriate tools and equipment should be given particular attention.

# 

# **References**

- 1. Jaffar M. Saeed, 1996; Dsability, Central Bureau of Statistics (CBS) Analytical Report December 1996 Khartoum
- 2. Khartoum Cheshire Home 2003, Annual Report.
- **3.** Ministry of Social Welfare and Human Development1998; Polices for disabled persons, paper Disabled Department.
- **4.** The National Center for Artificial Limb1996; the Disabled Care & Rehabilitation; Khartoum. Report
- **5.** National Social Insurance Fund ;The Work Injuries Act 1990 amended in 2004, , Department of Planning, Information and Statistics
- **6.** Ridda Ali S. survey of statistical study1997, about disabled children in Khartoum State inside the Institution which work with disability. Ministry of Social Welfare and Human Development, Disabled Department, Khartoum
- 7. Sudan Council of Voluntary Agencies (SCOVA) 2003, Directory of the NGOs working in the Sudan;
- **8.** Union of the Physically Impairment Against Segregation 1976; The Definition of Disability, Fundamental principles of Disability, London;
- **9.** United Nations, 2003-04; world programme of Action Concerning Disabled Persons, Concepts adopted within the System. Objectives, Background and Concept, accessed online at httr://www.un.org.
- **10.** UNESCO 2001, United Nations Educational, Scientific and Cultural Organization, Education and Disability, Website: <a href="www.unesco.org/education">www.unesco.org/education</a>;
- **11.** UN, 2003, Human Rights and Disability, office of the UN High commissioner for Human Rights-Geneva, Switzerland. httr://www.unhchr.ch/disability/intro.htm
- **12.** UN Statistics Diviation, 2003, Disability statistics-search result, Accessed online at <a href="http://www.unstats.un.org">http://www.unstats.un.org</a>.
- **13.** Vicki A. Freedman, Linda G martin, and Robert F.schoeni (2004)," Disability in America". Population Bullentin, vol.59, No.3, PRB, Washington; Website: www.prb.org.
- **14.** World Health Organization 1976, The Definition of Disability, Document A29/INFDOCI/1Geneva, Switzerland, Website: www.who.int