The Arab Council for Children and Development

Childhood Intellectual Disabilities
Definition, classification, symptoms, diagnosis, Causation (etiology) ant intervention programs

By
Dr. Osman L. Farrag
Professor of Environmental and Psychological Health
American University in Cairo

Introduction

The education or rehabilitation of disabled children is an exiting, challenging and rapidly developing and changing career. Historically, society's response toward disabled people has covered virtually the entire range of human reactions and emotions - from extermination, superstition, ridicule, pity and exclusion to intensive study, care and respect as human beings first and disabled second. The history of " special education" and the rehabilitation of children and youth with special needs is long heart breaking on one hand and colourful on the other; in itself an intriguing and illuminating study of mankind.

In developing countries the majority of disabled children live in rural and isolated areas. They have been largely ignored.

In several countries of the Arab world tremendous efforts have been made during the twentieth century to care for and rehabilitate physically handicapped children especially the blind, the deaf and those with mobility impairments.

However little had been done to those who suffer intellectual disabilities except for those who are mentally retarded. While those children with learning disabilities, or with Autistic spectrum and pervasive develop mental disorder are almost completely neglected. The major reasons for this neglect is the shortage of trained and highly qualified personnel and absence of specialised Arabic literature.

This book is probably the first source in the Arabic library that deals with the basic issues of characteristics, symptoms, diagnosis, treatment and intervention programs for children suffering from many of the prevailing intellectual disabilities. More emphasis is placed on categories of pervasive development disabilities and learning disabilities.

The first chapter starts with the definition of disability as: "a functional limitation within the individual, caused by genetic and or sensory impairments or limitations of opportunities to take part in the community on an equal level with others. The hindering factor behind this limitation is their inability to learn or perform tasks achieved by normally developing children."
According to the World Health Organisation (WHO), the development of the state of disability passes through three stages:

1. Impairment:
Resulting from a genetic or environmental factor (e.g. damage of brain or other tissues; loss of an or an, communication or language impairment, epilepsy; chromosome aberration…etc).

2. Functional Limitation:
Either partial or total; sensory resulting from the cause of impairment. Functional limitation could be of mild, moderate or serious degree.

3. Disability:
The state of inability to learn or perform tasks that can be achieved by a normal person of the same age, sex, educational and sociocultural background such inability would hinder partial or full participation in his community.

Because this chapter (the 1st) was concerned with the general concept of disability it was necessary to brief the reader on the classification of the many forms of disabilities and the place of intellectual disability among them.

Classification of Disabilities:

(1) Physical Disabilities:

a. Mobility:

e.g.: - paralis is of different forms
- Loss of limb/s
- Muscles tone and other defects

b. Densory:
- Blind
- Mute and hard hearing

(2) Social Disabilities:
- Juvenile delinquency
- Crime
- Drug addiction
- Broken homes and street children
- Illegitimate children

(3) Medical and disease disabilities
- Heart and respiration diseases
- Cancer
- Epilepsy
- Alzheimer
- Parkinson's

(4) Mental Disorders

a. e.g. Mental illness including
- Paranoia
- Schizophrenia
- Depression

b. Intellectual disabilities, including:
- Mental retardation
- Pervasive developmental disorders
- e.g. Autism, Asperger, Rett, P.DD-NOS, Childhood Disintegrative Disorder, Fragile X.
- Learning disabilities including:
Hyperactivity, attention deficit dyslexia and aphasia

This book will review briefly mental retardation and in more detail pervasive developmental disorders and learning disabilities.

This chapter (First) discusses briefly the size of the problem of disability. According to the World Health Organization, there are around 600

million disabled persons on our plane earth which compose 10% of its population. Because of the absence of surveys and statistical research reports in the Arab world, we can only estimate the number of disabled persons in Arab countries according to WHO rates as about 30,000,000 persons (out of a total population of 300 million). However, reports of some small scale studies and surveys carried out in few countries in the Arab world revealed that the percentage of disabilities is eventually higher than 10% (between 12 and 14). This is due to specific differences between the quality if life in industrial countries (where the rate of 10% was drawn from scientific research surveys) and that in the developing countries of the Arab world as well as differences, cultural variables and access to basic health factors (e.g. malnutrition, closed marriages within the family, high illiteracy rates, poor housing and sanitation, high childhood accidents and labor rates, pollution and chemical poisoning, high fertility and short spacing between births ..... etc)

The first chapter also was terminated by a brief review of the major causes of disability among children and youth. The bulk of the book starting from chapter two will concentrate on intellectual disabilities.

The second chapter represents a review of mental retardation, which is defined by the American Association of Mental Deficiency as "a combination of a low intelligence score and problems in adaptive behaviour, which occurs during the child's developmental stage." This is merely one definition of many others were reviewed.

Intellectual functioning (intelligence) as used in intervention programs or "special education" is most often measured by a score on a standardized intelligence (I.Q) test. The most important of these tests is Stanford Binet test and WISC - R test. I.Q. scores are distributed throughout the population according to a phenomenon called normal curve:

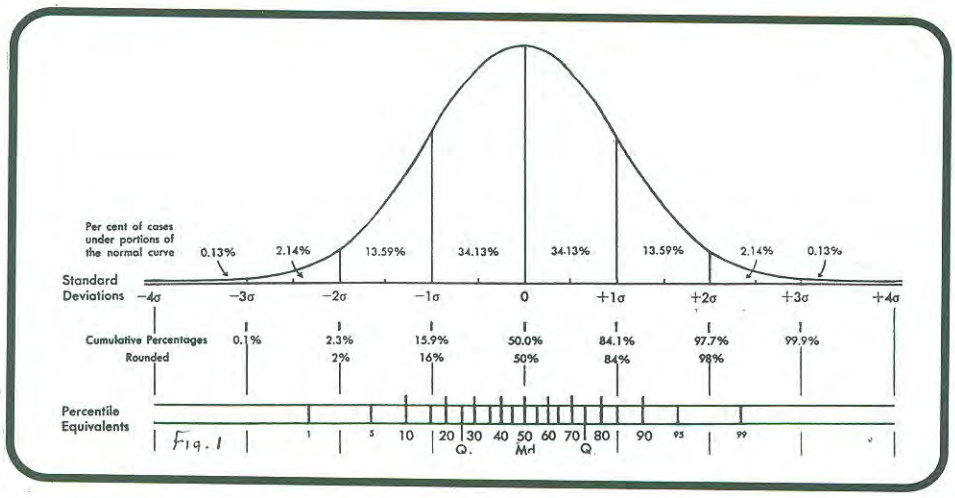

Fig. 1

Adaptive behavior is defined as "the effectiveness or degree with which the individual meets the standards of personal independence and social responsibility expected of his age and social group "the two mostly used scales for measuring adaptive behavior are:

1. The American Association on Mental Deficiency Adaptive Behavior Scale (AAMD ABC).
2. The Vineland Social Maturity Scale

There are several classifications of mental retardation. The most widely used in educational circles are:

1. The mildly retarded group usually described as "educable" whose "I.Q" ranges between 50 and 70 (between 2-3 standard deviations). They compose about 80% of the mentally retarded children.
2. The moderately retarded - described as "trainable" with an I.Q ranging between 35 and 50. They can develop basic feeding, dressing and simple academic skills. Their occupational skills are

limited to routine chores. They compose 10-14% of mental retardates.

3. Severely (and/ or) profoundly retardates scores are below 35-25. Their independent functioning could be expected in limited areas. In their adulthood they require continues care and protection.

Causes of mental retardation are either genetic or a wide range of environmental factors: e.g. infections (rubella, meningitis); toxification (lead, mercury); trauma (accidents that cause brain damage); chromosomal abnormality (down syndrome); metabolism and malnutrition (PKU); Gestional disorders (premature birth, hydrocephally, microcephalus).

Chapter 3,4 and five review the group of disabilities collectively known as the "Pervasive Developmental Disorders" (P.D.D), or "Autistic Spectrum" as some scholers in the field prefer to call it (figure 2).

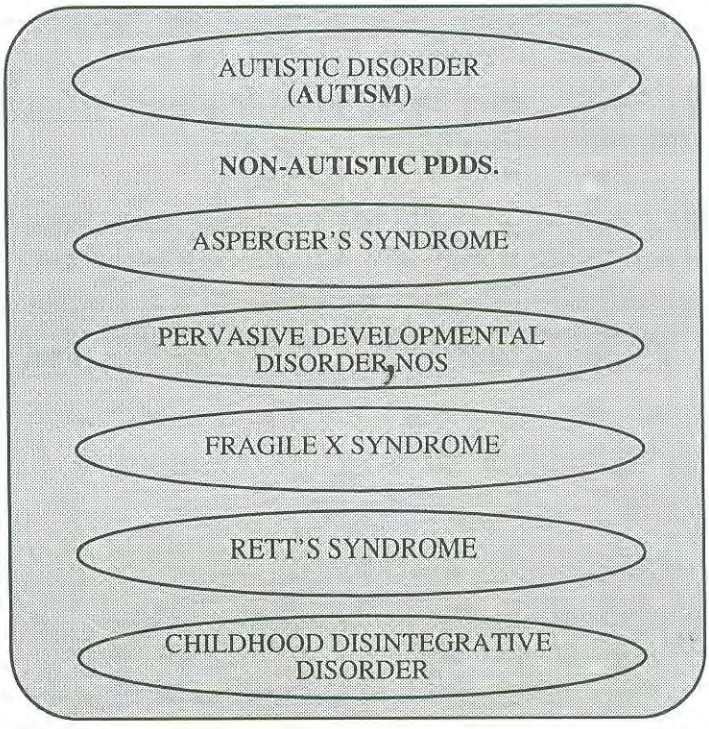

Figure 2 The Pervasive Developmental Disorders: Autistic Spectrum Disorders.

The fact that Autism and other non autixtic P.D.D. disorders are classified as "developmental disorders" means that they are conditions a child is believed to be born with, or born with a potential for developing.

Although present research have not reached a conclusion of what causes these intellectual development disorders, we know now that they are the result of an abnormality in the structure and functions of the brain. Although technology still does not yet allow us to see much of how nerve cells grow or come together in the brain, or how information is passed from nerve to nerve, there is an increasing evidence that the problem associated with Autism and other syndromes of P.D.D. are the result of structural differences in the brain that arise during pregnancy - either due to environmental factors that injures the brain or due to a genetic factor that interferes with typical or normal brain growth and development.

After defining and classifying the categories of P.D.D; the third chapter reviews the definition, characteristics, symptoms and diagnosis of Autism starting with history of its discovery (by Kanner in USA and Asperger in Austria in 1943), its relation with mental retardation, its prevalence, etiology, intervention and rehabilitation with emphasis on individualized educational programs.

About eighty percent of autistic children have some degree of mental retardation or suffer, in addition to autism, from one or more of at least 15 other syndromes (e.g. learning disability; CP; fragilex; epilepsy; P.K.U.; Williams syndrome; tuberous sclerosis.... etc).

Chapter three also emphasizes the important of differential diagnosis and assessment before designing intervention programs or reaching a realistic prognosis

Research reports estimate that only about 10-15% of autistic children passing through an intensive individualised educational program can remarkably progress and achieve a normal independent life. The majority of other autistic children will require continuos care during adulthood.

Intervention

Intervention is a general term for all the efforts made on behalf of disabled individuals. The overall goal of intervention is to eliminate or at least to reduce the obstacles that keep the disabled person from full and active participation in society.

There are three basic forms of intervention services:

- Preventive (keeping possible problems from becoming serous handicaps);
- Remedial (overcoming handicaps through training education and rehabilitation);
- Promotive and compensatory (giving the disabled person new ways of dealing with his or her disability).

Preventive efforts are most promising when they begin early in life -even before birth in some instances- the book explores some of the most recently developed methods of preventing handicaps (e.g. genetic counseling, genetic therapy and screening early in infancy for metabolic disorders, chromosome abnormality, developmental disability conditions.... etc) and other conditions that produce disability. The book explores, too, the efforts being made in social, educational, psychological and medical programs to stimulate infants and young children to acquire skills that most children learn normally without special help.

Unfortunately, preventive programs have not, so far, given due consideration in the Arab world and other developing countries or have only just started in few communities. Some researches estimate that it will take well into the 21st century before we are able to reduce disability rates by even a small percentage. In the meantime we must count on remedial, promotive and compensatory efforts to help the disabled to achieve fuller and more normal independent life.

Remedial programs, as dealt within this book, are those largely supported by educational institutions and social agencies. In fact the term remediation is primarily an educational term; the term rehabilitation has been used as to mean; like education, to teach the disabled person the basic skills needed for achieving an independent life. In schools these skills may be academic (reading, writing, mathematics, self care and computing skills.); or social (e.g. getting along with others, pragmatic communication language, following instructions, schedules and other social daily routines) as well as vocational skills to prepare the disabled for jobs in the community and to develop work habits, attitudes and safety.

The underlying assumption of both remedial and habilitative programs, as presented in our book is that disabled people need special help if they are to succeed in the "normal" world. Whenever possible, this special help is designed to teach the disabled the same skills that the non-disabled persons have only through different or more intensive methods and techniques. Chapter 4 reviews asperges syndrome and chapter five reviews Rett's syndrome along the same lines.

Chapter 6 & 9 deal mainly with learning disabilities. Learning disabilities describe a group of children who have hindering factors in the development of associated communication and language, speech, reading and other academic areas.

Such disorders are not due to mental retardation, autism or sensory defects (e.g. like vision or hearing defects). Rather they are characterised by discrepancy between their scholastic achievement and their actual intellectual abilities.

Specific learning disabilities means a disorder in one or more of basic psychological processes involved in understanding or in using language (spoken or written - receptive or expressive) which may manifest itself in an imperfect ability to listen (attention), think, speak, read, write, spell or do mathematical calculations. It could be expressed in one or more of the following forms: hyperactivity; attention deficits; dyslexia; aphasia; . etc.

These disorders are intrinsic to the individual and presumed to be due to central nervous system dysfunction. Examples of these are:

- Metabolic abnormality in the brain (especially in the cortex layer); malfunctioning of the cerabellar vestibullar (which connects the inner ear with the cerebellum); dysfunction in the section of the thyroid gland (hyperthyrodism or hypothyroidism); disturbance in the secretion of neurotransmitters; allergies to some foods or food additives or chemical environmental pollutants (e.g. lead, mercury, asbestos); other factors causing learning disabilities could be psychological or infectious diseases (e.g. meningitis or Encephalitis)

Chapters on learning disabilities covered four categories of the different forms:

(1) Hyperactivity
(2) Attention deficit
(3) Dyslexia communication
(4) Aphasia disorders

Each of these categories was reviewed discussing in detail the 4 following areas:

a) Characteristics & symptoms
b) Etiology
c) Diagnosis and prognosis
d) Intervention

Aside form the above four categories of learning disabilities there are several others that were not elaborated in these chapters (e.g. mathematical education and reasoning; visual and/or auditory perception impairment ... etc.)

The term learning disability is not meant to be used for children who are: (1) mentally retarded or (2) those who are termed slow learners or borderline cases (with I.Q. of 70-85) or (3) those who are having a temporary difficulties in learning due to physical health problem (e.g. anaemia) or sensory impairment (hard hearing or poor vision).

The term is meant to identify children with a severe discrepancy between intellectual abilities and scholastic achievement. Learning disability

might affect children with an average I.Q. (85-115) as well as those who are bright, gifted or genius, with I.Q. high above 115 150. In fact history tells us about several genius world leaders who suffered in their childhood from learning disabilities (e.g. A. Einstein; T. Edison; J. Kenedy, W. Disney; Beethoven, L. Pasteur; L. Da Vinci; G. W. Buch).

In individual suffering from learning disability might exhibit symptoms of either or a combination of two or more of the different above listed categories. One example of the common combinations that is widely prevalent is attention deficit/hyperactivity disorder (AD.HD) which affects 5-7% of the school population in USA.

The Situation in the Arab World

In connection with the state of recognition and rehabilitation of intellectually disabled individuals in Arab countries the book pointed out the shortages and weaknesses that need immediate consideration and action. The following are few of them:

1. The absence of the basic data and statistics on prevalence (size of the problem) of each category of intellectual disabilities, distribution (according to age, sex, geographical and socio-economic variables); and causality.
2. Shortage of programs and facilities of intervention. While the estimated size of intellectually disabled is roughly between 7-10 millions (out of a total population of 300,000,000) those who have access to services do not exceed 400,000.
3. The drastic shortage of qualified personnel, not only educators but even more serious for those speech therapists, occupation therapists, physiotherapists, psychologists and specialized medical doctors. This is due to shortage of preparation and in service training programs.
4. The absence of integration policies and facilities that encourage and prepare the disabled to participate on an equal level in the community.

These, and many others are pressing problems hindering access to full-fledged services that require a long term plan of scientific research in the many aspects of treatment; prevention and promotion programs, as well as the need for a political will and determination.

لقد عانى المعاقون من العزلة والحرمان والإهمال والنبذ والضياع لفترات طويلة ؛ فعزلوا عن المجتمع في زوايا النسيان حتى من جانب أسرهم ، حيث يتم التعامل معهم من باب الشفقة من ذويهم ومن المتعاملين معهم ، ووجدت بعض الجمعيات، التي كانت ترعى قلة منهم مقابل أجر مادي ، وكانت معالجة أسباب الإعاقة بدائية وغير علمية ، وكان البعض يفسرها على أنها من غضب الله عليهم وهم من ذلك براء . وحتى عندما بدأ العلم يكشف عن أسباب الإعاقة ظل المجتمع يصمهم بوصمة العجز ، ويعتبرهم عبئاً كبيراً عليه وفئة غير منتجة .

وإدراكاً من المجلس العربي للطفولة والتنمية لدوره المنوط به منذ إنشائه ، ومن خلال الرؤية الرائدة لصاحب السمو الملكي الأمير طلال بن عبد العزيز رئيس المجلس العربي للطفولة والتنمية منذ العام ١٩٩١ ، لرعاية وحماية وإدماج الطفل المعاق ، وفي الرؤية التي توجت بنشر وتعميم البرنامج المنزلي للتدخل المبكر لتدريب أمهات الأطفال المعاقين ، يأتي هذا الكتاب عن الإعاقات الذهنية ، في مرحلة الطفولة ليكون معيناً ومرشداً لأسر الأطفال المعاقين ، وكذلك - أيضاً - للعاملين في مؤسسات رعاية وتأهيل الأطفال المعاقين ، ومختلف مؤسسات الإدماج الاجتماعي .

ومن أجل أبناء هذه الفئة من المواطنين الذين تعامل معهم الدكتور عثمان فراج - لأكثر من خمسة وأربعين عاما في مجالات العمل الاجتماعي ، وتأهيل الأطفال المعاقين - في قاعات الدرس والجامعات ومراكز التدريب والعيادات النفسية والنوادي الرياضية والمؤسسات الخاصة ، أعد هذا الكتاب، الذي حرص المجلس العربي للطفولة والتنمية على نشره ، لإفادة كل هؤلاء .