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SERVICES FOR THE MENTALLY HANDICAPPED CHILDREN AND ADULTS. THEIR DEVELOPMENT AND CURRENT PROVISIONS IN ENGLAND, GERMANY AND SAUDI ARABIA

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DECLARATION

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ABSTRACT

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SERVICES FOR THE MENTALLY HANDICAPPED CHILDREN AND ADULTS. THEIR DEVELOPMENT AND CURRENT PROVISION IN ENGLAND, GERMANY AND SAUDI ARABIA

The research traces the development of medical, educational and social services provided for the mentally handicapped children and adults in England, Germany and Saudi Arabia, and describes the current situation regarding such services in the three countries. The work considers the different social aspects of mental handicap, such as attitudes towards the mentally handicapped, and problems facing families with mentally handicapped children. It also outlines the different methods of educating and training people with mental handicap, and the development of normalisation concept.

The work describes a case study of a special private centre for the mentally handicapped children in Jeddah, Saudi Arabia, and highlights the development of this project in the context of the special cultural and social circumstances in Jeddah.

The writer concludes that a great deal of progress has been recently made, especially in the second half of this century, in the field of providing different aspects of services to the mentally handicapped. However, the study confirms that there is still a significant amount of work to be done both by public and private sectors, in order to meet the special needs of the mentally handicapped people, and to achieve their integration into community life.

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INTRODUCTION:

It has been estimated that about 10% of the world's children under the age of 15 are disabled. In 1975 there were about 18 million disabled children in Africa, 88 million in Asia, 11 million in Europe, 13 million in Latin America and 6 million in North America. It is expected that these figures will increase by about 35% by the year 2000 unless some radical changes can be introduced to provide effective preventive measures and rehabilitation services (International Children's Centre, 1981).

In the middle ages, general care of the disabled and handicapped fell on family, neighbors and religious institutions. In England, it was only in 1601 that the Poor Law Act imposed a duty on the local authorities to provide for the disabled. The seventeenth century witnessed a modest progress in the care for the handicapped people and it was not until the nineteenth century that special provision was made for the mentally disordered (Byrne and Padfield, 1990). But the real improvement in services happened only during the twentieth century, and in particular after the end of second world war.

It was during the early 1950's that global awareness of the need to provide care of all sorts for disabled people became evident. Efforts exerted by both public and private sectors in different countries gathered momentum. National and International organizations were formed (1), and in very short time gained recognition and support. A major public awareness of their special needs gave their cause a human and sympathetic attitude. New ideas and social concepts promoted accepting the mentally handicapped as equal members of the society.

In addition to activities carried out by local organisations and individual countries, several initiatives were taken by the United Nations and its specialized organizations (2) to disseminate examples of good practice and provide International leadership in this field. These efforts were given considerable impetus during the "International Year of Disabled Persons" 1981. A resolution was adopted by the General Assembly of the United Nations (Appendix 1) which highlighted the steps to be taken in order to improve the handicapped people's situation, and specifically:

"- Reiterated the need to promote the realization of the right of disabled persons to participate fully in the social life and development of their societies and to enjoy living conditions equal to those of their citizens.
- Requested that high priority is given to the formulation and implementation of regional programmes related to equalization of opportunities for disabled persons.
- Invited relevant non-government organization to expand their programmes related to the disabled.
- Urged different organizations and bodies to undertake measures to improve employment opportunities for disabled persons."

There are many types of known disabilities. This work, however focuses on one type of handicap, the mental. The term, "mentally handicapped" is a term used to describe a section of the public who possess a lower than average level of intelligence (Senior, 1985). In Britain, it is estimated that around 10% of the entire British population are disabled in some way or another, of whom 20-25% are mentally handicapped (Byrne and Padfield, 1990). There are, however, different levels of mental retardation, which specialists generally agree on, namely, mild, moderate, severe and profound. These levels are related to different levels of I.Q (Intelligence Quotient) and adaptive behaviour (Senior, 1985).

Mentally handicapped people suffer from a permanent disability which prevents their brain from developing as far, or function as well as that of a normal child. Those people, however can be helped at all stages of their life, and in most cases, the results of such help prove to be effective and beneficial, both to the individual and the society.

Help can be provided from as early as birth (Early Intervention), followed at a later stage by special teaching and training children (Special Education), to provide them with an opportunity to be employed with tasks compatible with their abilities (Employment), and to cater for their day to day needs by providing them with homes and shelters (Residential care).

Services of many organizations and individuals are required to provide a satisfactory level of care for mentally handicapped people. Local Authorities, special educationalists, social workers, physicians, dentists, psychologists and therapists are all required to work together and cooperate towards such aim. This requires a high level of organization and interest.

In the United Kingdom (UK), services to the mentally handicapped are provided by a combination of statuary and voluntary bodies. These services cover medical treatment, education and other services provided by the community. On the international level, one of the significant specialised activities, to organize and promote the cause of people with mentally handicap was the INTERNATIONAL LEAGUE OF SOCIETIES for persons with Mental Handicap (ILSMH), which has its headquarters in Brussels. This organization started by a small group of national parents societies in 1960, but developed during the nineteen eighties into a worldwide federation of more than 100 parents professional societies in more than 70 countries (Von Stedingk, 1985).

In 1968, the General Assembly of ILSMH adopted a Declaration of General and Special Rights of the Mentally Retarded Person. This resolution confirms the rights of people with mental handicap to proper medical care, education, training rehabilitation, and a decent standard of living, whether the person was living with his own family, or with foster parents. It also calls for protecting the mentally retarded person from exploitation, abuse and degrading treatment. Three years later, the same declaration was adopted by the United Nations General Assembly as the Declaration of the Rights of the Mentally Retarded Person (Appendix 2).

Another resolution adopted by the United Nations in 1979 (Appendix 1), stressed in many ways the need to direct attention to support and strengthen activities in developing countries, including the strengthening of organizations of disabled persons.

It also invited member states to;

> "promote close and effective cooperation through a transfer of technology and of the results of research and exchanges of information on the prevention of disability and the rehabilitation of disabled persons".

The developing countries had more than their share of this problem. It was indicated that 80% of the total number of people who suffer from disability of one form or another live in developing countries. In 1980, it was estimated that 10% of the world's 1400 million children under the age of 15 were disabled (International Children's Centre, 1981).

Globally, it was recognised that, while care for the handicapped people in the developed and industrial countries, benefited from the superior organization, social structure and humanitarian motivation which existed in such countries, there was insignificant and inadequate support or provision to improve the conditions of people suffering from all forms of handicap in the developing countries. It was only after the Second World War that various government, private, charitable and other organizations became involved in supporting health, educational training and therapeutic programmes established to look after the handicapped people and improve their life in developed countries, and particularly in Western Europe (1). Meanwhile, there was little support and attention in the developing countries due to inferior financial, social and public structures. Problems such as those of the mentally handicapped people came low in the list of priorities, both on the public and private sector. There are however, indications that this situation is gradually improving as a result of the international organizations work, and assistance by western societies to local bodies.

The term "developing country" covers a large number of countries in a wide variety of economic and social situations. The oil producing countries, including Saudi Arabia, lie at the top of the range of the "developing countries". As a result of the immense wealth earned during the oil boom, the affluent oil-rich countries can afford to provide many services to the handicapped, both by public and private sectors.

In Saudi Arabia, government agencies are responsible for looking after people with all types of disabilities. All services provided, however, were established during the last two decades, and is limited to the more populated areas of the Kingdom. In general, there are many private and charitable organizations functioning in the country, encouraged by strong religious and social motivation. However, very few of these charities are looking after disabled people, and with the exception of the one centre in Jeddah, the organizations concerned with mentally handicapped people are almost non-existent.

The Centre in Jeddah, the "Help Centre", is a charitable organization, established by the Juffali Family in Jeddah in 1987, and is gradually developing into an oasis for the mentally handicapped children and their parents. The writer has been involved with this Centre since 1988, and witnessed its remarkable growth since inception. The Centre currently occupies temporary accommodation, and is expected to move to a specially built facility in December 1994.

Part One of this thesis introduces the thesis topic and covers the general aspects of mental handicap. 'Part Two' discusses the development of services for the mentally handicapped in England, while 'Part Three' describes such services in Germany. A case study for a special centre for the mentally handicapped children in Jeddah is discussed in 'Part Four', and general conclusions and recommendations are outlined in 'Part Five'. Because the various sections of the thesis describe mental handicap in the context of different countries, relevant literature is referenced throughout the thesis rather than the more usual method of gathering the major amount of the literature into a single chapter.

This thesis is mainly concerned with highlighting the main aspects of mental handicap and describing the progress made towards improving care for people with mentally handicap. The work will trace aspects such as medical care, education, training and general care for the mentally handicapped persons in three locations where the writer has come in contact with and experienced such development, i.e England, Germany and, Jeddah, Saudi Arabia. Additionally, this thesis attempts to set the development in Jeddah in the context of services for the mentally handicapped in the European countries mentioned. As education is emerging as one of the most important aspects of such services, this work includes a description of three facilities especially built to serve the special educational needs of such people.

NOTES:

(1) Such as the International League of Societies for Persons with Mental Handicap (ILSMH) in Brussels, The Royal Society For Mentally Handicapped Children and Adults - (MENCAP) in the UK (Chapter 4), German Society for people with Mental Handicap (LEBENSHILFE) in Germany (Appendix 4) and the Joseph P. Kennedy Jr. Foundation in the USA (Appendix 3).

(2) Such as the United Nations Educational, Scientific and Cultural Organization (UNESCO), International Labour Office (ULO), the World Health Organization (WHO) and the United Nations Children's Fund (UNICEF).

PART ONE - CHAPTER TWO:
GENERAL ASPECTS OF HANDICAP

The objective of this Chapter is to provide a general introduction to the basic aspects of mental handicap. Section One covers introductory issues to the subject such as the definition, the causes and the main types of mental handicap. Section Two outlines some social aspects of mental handicap such as the effect of having a mentally handicapped child in a family, attitudes towards the mentally handicapped, their education and training. Section Three discusses the general development and aspects of the normalization principle, a sophisticated concept in providing services to the handicapped.

SECTION ONE: DEFINITIONS

A. General Handicap:

In 1980, the definition given by the World Health Organization for the term Handicap is:-

> " In the context of health experience, a handicap is a disadvantage for a given individual resulting from an impairment or disability that limits or prevents the fulfillment of a role that is normal (depending on age, sex and social and cultural factors) for that individual". (Senior, 1985)

There can be many causes for people becoming disabled or handicapped; among the most prevalent ones are infectious diseases, malnutrition, congenital defects and accidents,

(International Children's Centre, 1981).

The ensuing handicaps can be divided into several groups such as:-

a. locomotor problems, due for instance to birth injury, poliomyelitis accidents.

b. visual handicaps ranging from the blind to partially sighted, especially frequent in countries where trichoma or vitamin A deficiency prevail.

c. hearing handicaps ranging from the deaf to partially hearing.

d. mental handicaps including mentally retarded and brain-damaged children, for instance after birth injury.

e. maladjustment due to emotional or social problems, not to mental retardation, often related to family, especially common in abused and neglected children.

The scope of this work, however, is limited to one type of handicap, namely mental handicap.

B. Mental Handicap:

Mental Handicap is the term used to describe a section of the public who posses a lower than usual average level of intelligence. A child is considered mentally handicapped who, during the early development period, exhibits significant subaverage intellectual functioning accompanied by impairment in adaptive behaviour (Senior, 1985).

By using tests which measure 'intelligence', mental abilities could be defined. Most people have a test score or IQ (intelligence quotient) between 90 - 110, which is defined as 'normal'. Those with IQ s below 70 are said to have 'subnormal' intelligence (Senior, 1985).

People with IQs between 70 and 50 usually have difficulties in learning and in developing skills. This range of mental handicap is called mild mental handicap. People with IQs below 50 are said to be severely mentally handicapped. They have severe learning difficulties and usually do not develop the ability to reason in any depth. They often have major damage to the brain or nervous system, or easily recognized genetic conditions such as Down's Syndrome. These are also children whose mental ability is so poor that one can not really measure their IQ. This range is (less than 20) described as profoundly mentally handicapped (Senior, 1985). More severely handicapped people often suffer from physical as well as mental disabilities. The most common related physical disabilities are spasticity, epilepsy, blindness, hearing defects and heart problems. Mental handicap is incurable, like any other permanent disability, but there are certain precautions that could be taken in order to reduce the risk of giving birth to a mentally handicapped child, or of a child becoming mentally handicapped. There are three main types of prevention known as primary (before the moment of conception when parents 'at risk' of giving birth to a mentally handicapped child can be advised of the risks) secondary, (concerns the child when it is in the womb), and tertiary (where the child has already been born). (International Children's Centre, 1981).

C. THE CAUSES OF MENTAL HANDICAP:

Establishing the causes of mental handicap has always proved difficult and even today, two-thirds of cases are due to unknown factors. Many cases of severe handicap are due to medical conditions and the causes are better understood but they are still difficult areas of definition. Some of the main causes of mental handicap are listed as follows, (Senior, 1985):-

FOETUS	Chromosomal Abnormalities
	Disorders of the Central Nervous System
	Metabolic Disorders
	Disease and Infection.
MOTHER	Disease and Infection
	Drug Abuse
MOTHER/FOETUS	Rhesus Incompatibility
BIRTH	Low Weight

	Childbirth Problems
NEW-BORN CHILD	Infection
CHILD-ADULT	Accident
	Social and Environmental Factors.

D. THE MAIN TYPES OF MENTAL HANDICAP:

The most commonly known types of mental handicap are identified as follows, (Senior, 1985) and (Stopford, 1987):-

a. Down's Syndrome:

It is the largest single cause of mental handicap, and accounts for around one third of all cases of severe mental handicap in children. It was sometimes referred to as 'mongolism,' due to the characteristic facial appearance which resembled that of the Mongolian races, but this term is no longer used. The condition was first described in 1866, by Dr. John Langdon Down. This handicap is caused by a chromosomal abnormality which means that there is an additional chromosome in the cells. It is rarely inherited and the cause of the handicap may be related to the age of the mother, as the rate of incidence increases considerably where the mother is older. The age of the father is much less important but the incidence may increase where the father is over 60 years old.

b. Autism:

Little is known about the causes of autism. It is believed to be probably caused by an organic abnormality of the brain dating from before or even after birth; it can occur up to three or even five years of age. There are no traceable physical defects and a fifth of autistic children have a normal IQ level. Autistic children have difficulty in relating to their relatives and fail to offer the usual rewards in terms of affection and belonging.

c. Brain Damage and Cerebral Palsy:

Babies who are born normal, but encounter some form of birth trauma or injury may suffer brain damage, and the nature of their handicap will depend on the part of the brain affected. The result could be a reduction in the level of mental ability, but in some cases the damage to the brain may cause mental and physical handicap known as cerebral palsy. There are several forms of cerebral palsy, including athetosis, ataxia and the best known, spasticity. The spastic child may not be mentally handicapped, but cerebral palsy is the most common form of physical handicap amongst mentally handicapped people. Because of the difficulties of communication, there has been a tendency for the intellectual abilities of people suffering from cerebral palsy to be underestimated.

d. Hydrocephalus, Anencephalus and Spina Bifida:

Hydrocephalus is one of three forms of congenital malformation relating to disorders of the central nervous system. It is most commonly known as 'water on the brain', where an excess amount of cerebrospinal fluid is present and the head expands to accommodate it. It can now be treated by the use of a valve which drains off fluid to the heart. Only 10% of children born with spina bifida are brain damaged. All anencephalic children are either miscarried, die stillborn, or die shortly after birth. These account for around a fifth of live births in this group of handicaps, but due to their short life, they are not present in the community . Hydrocephalus and spina bifida may not always cause mental handicap but where they do, the handicap can be very severe, causing blindness, severe spasticity, paralysis and profound mental handicap.

e. Other Forms of Handicap:

These extend over a wide range of mental and physical disabilities caused by an even wider range of genetic factors, infections and diseases affecting the normal reproductory process. They will in most cases lead to brain damage, or a range of specific physical abnormalities usually identified as some form of 'syndrome'. Some of the effects of brain damage is hearing impairment, behavior disorders, language disorders, learning disorders, clumsiness (Senior, 1985).

SECTION TWO: SOCIAL ASPECTS OF MENTAL HANDICAP:

A. THE FAMILY WITH A HANDICAPPED CHILD:

The birth of a mentally handicapped child in the family is a devastating experience and can drastically affect the family's life pattern. It follows a period of preparation and joyful anticipation which is suddenly brought to a dramatic end. Usually it is a new event totally outside the experience of everyone concerned and causes different reactions within the family. In some cases the psychological impact of such event threatens the whole being of the parents, and shatters the hopes rested in the unborn child.

Reactions within the family towards such events depend, however, on many factors, such as the emotional maturity and education of the parents as well as intra-family relationship. In any case, the handicapped child needs much more of the parent's time and consideration and is sometimes experienced as a burden, including an economic one to the family. The siblings may also become jealous or develop negative attitudes towards the handicapped brother or sister. All this may cause permanent disturbances in the whole family relationship. These consequences tend to become worse with time passing unless appropriate measures are taken to diminish them.

It is common experience that impairments and disabilities have many consequences to the child and to his or her family as well as to the society. Some of these consequences are directly connected to the functional limitation preventing the child from enjoying normal peer contacts and other social and educational activities, typical for his or her age. There are also problems arising from the attitudes of the parents, which sometimes may lead to an overprotection of the child and cause emotional problems such as overdependence and immaturity.

Studies of the practical problems associated with the up-bringing of handicapped children indicated the high demands placed upon such families. Practical needs of mothers, the effect of the handicapped child on internal family relative and external social relations can cause the family to experience stress (Harrisson, 1977), and would, therefore, require external support. While basic family needs such as food, clothing and shelter may not be affected as a result of such stresses, many other aspects of normal family needs and relationship can suffer. Such families under stress, may become deprived of their leisure time, suffer from reduction of frequency of parental interaction, and face disturbance in communications of all kinds between all family members. Generally, these families need a range of services to cater for the variety of needs and reflect a situation in which there is no cure and which such service should continue throughout the full lifetime of the mentally handicapped person.

Inspite of problems and hardships imposed on the family as a result of having a handicapped child, there seems to be many advantages to the children for keeping them within the family. Within its own family, the mentally handicapped child can practice the daily routines of washing, dressing, eating, going to school, etc.., on regular basis. With supportive educational programmes, and full integration within its own family and the society as a whole, results in most cases to a noticeable improvement in the child's general behaviour, attitudes and overall development (Lebenshilfe, 1983).

B. EDUCATION AND TRAINING:

For many years the abilities of the mentally handicapped have been greatly underestimated. However, in the last thirty years or so, there have been some fundamental changes as to general knowledge about mental handicap, and it is only relatively recently that communities have begun to provide them with skills and systematic teaching. It is now accepted that mentally handicapped people are capable of learning to a far greater extent than it previously thought possible, provided they are given skilled help and time to learn (Mittler, 1979).

The handicapped youngster's special needs have been recognised as early as 1601 in Britain (1). The state became effectively involved in 1899 by passing the Elementary Education effective and Epileptic Children Act, which made firm requirements to make special provision for handicapped children. Since then, there has been an ongoing debate on the issue as to whether or not the special educational needs of handicapped children can best be met in ordinary schools with the main stream of children, or in specially equipped and staffed segregated schools (Topliss, 1982).

In the field of education, integration and segregation are the terms used to describe the two different approaches towards providing special education for the mentally handicapped. Integration in education has been supported by legislation in many countries, and favoured by many parents of mentally handicapped children. The main argument for this approach was that a handicapped child in a special school for the mentally handicapped is segregated from his peers, while that same child in an ordinary school would be integrated into the local child community (Mittler, 1979).

Another positive advantage brought up by the supporters of integration is that there is less need for costly special buildings and additional highly specialised staff, while existing educational facilities can be extended to accommodate more children. Those who argue in favour of integration stress that a handicapped child adopts more easily to living in ordinary society the earlier he or she begins to do so. The non-handicapped grow up with the handicapped and learn to accept them and their disabilities from the beginning (Von Stedingk, 1985).

On the other hand, opinions favouring the provision of special schools for the handicapped children go back to the 1880's, when Moberley, the Chairman of the London School Board argued that if mentally children were to reach their full potential, they needed to be taught at a slower pace and in smaller classes than would be possible by merely absorbing them in ordinary schools (Topliss, 1982).

Another strong supporter of special schools for the mentally handicapped is Peter Mittler:

> "The assumption is made that special schools 'segregate' and normal schools 'integrate'. But the issues are far more complex than this. Not only is there a whole range of provision from extreme segregation to total integration, but a school which may at first sight appear to fall at one extreme or the other in terms of its 'label', may, in fact be operating very differently in real terms. For example, a class of handicapped children attached to an infant school may in practice never work or play with normal children and lead a segregated existence in all but name; similarly even when a special school is on the campus as a normal school, there need not necessarily be any contact between staff

> or children. A residential school in a remote rural area may become fully part of the community, and its pupils accepted as local children. A handicapped child may even be in an ordinary classroom everyday but may be isolated socially and educationally from other children and from the activities of the class.. Merely placing handicapped children in a normal school does not guarantee that any social or educational integration will take place" (Mittler, 1979).

Mittler refers to Lubokoviski, a Russian expert on special education, who supports the argument against integration, and suggests that it can produce some negative aspects to the development of the child (Mittler, 1979). He argues that when a mentally handicapped child is integrated into the ordinary education system, and to be placed among normally developing children, the handicapped child finds himself in a situation of inequality, which results in exposing him/or her to far more difficult circumstances than the other children.

A meeting for UNESCO Experts on Special Education (1981) agreed that while the purpose of and goals of education are essentially similar for all children, the techniques required to help individual children progress may be different. It also accepted the fact that some children will require substantial modification of the educational programme, while others will require only a minor variation.

C. ATTITUDES TOWARDS THE MENTALLY HANDICAPPED:

The history of the attitudes of communities towards children born with sever deformities or mental handicap has been identified as following four main reactions in chronological order:

(1) Extermination
(2) Segregation
(3) Second class citizenship
(4) The granting of equal rights as citizens.

In the Third Reich these handicapped persons were defined as "valueless lives". They received no help or support and were victims of liquidation and euthanasia programmes (Hoss 1983). Extermination is still practised in some societies, but the early initiatives of major religions orders helped to produce a more caring attitude toward those unable to fend for themselves.

Ryan and Thomas (1991) however, relate most of the early ideas and resulting attitudes towards the mentally handicapped to religion, and state that the idea of handicapped children being a punishment for the sin of individual parents, is seen clearly in Luther. Another common idea in this respect was that the abnormal children were the result of sexual intercourse between a woman and the devil. In Europe, giving birth to a handicapped child was grounds for considering a woman to be a witch.

In the early days of the eighteenth and nineteenth centuries, the prevailing attitude towards the mentally handicapped was mostly hostile. Even in the early years of the twentieth century, there was no real distinction made between mental handicap and mental illness, "mad" people were considered bad, a nuisance, evil beings, they were controlled and locked away in asylums and private madhouses. Separate institutions for the handicapped were provided under the Idiots Act, 1886 (Byrne and Padfield, 1990). Other commonly used classification of the mentally handicapped were, "subnormal, imbeciles, feebleminded, and moral defectives".

Inspite of the general improvement of public attitude towards the mentally handicapped by the turn of the twentieth century, a number of people concerned with the welfare and social advancement of the mentally handicapped expressed their concern about the treatment of such people and the ethical implications of such attitudes.

> "People with learning difficulties are the most oppressed of all minorities. They are both rejected and sentimentalized - objects of pity, mawkishness and whimsy. There is a great danger that we may compound the overall oppression aimed at their submission. The system tries to break their spirit through enchaining both them and us. At stake here, is not only their freedom but also our own" (McGee, 1985).

Another dimension of this aspect is reflected by normal people's tendency to exercise dominating behaviour towards the mentally handicapped.

> "Professionals, nurses, social workers and others are taught to dominate and control people with handicaps. The words happiness or joy are rare in individual programme plans. We have to turn our backs on domination and control strategies, bring justice to people with handicaps and make sure that what comes out of our mouths and from our hands is fair, warm and affectionate". (McGee, 1985).

The second half of the twentieth century witnessed a remarkable change in the public attitude in the industrialized countries towards people with mental handicap. The emergence of such positive attitude could be referred to a feeling of guilt by the civilized community, trying to counteract the previous passive rejection they had experienced. Their cruel treatment in Germany under the Nazi reign was an experience no one wants to remember (Ryan and Thomas, 1991).

The pioneering work on special needs of the handicapped by Itard (1894), Seguin (1870) and Montessori (1912) as cited by Segal (1984), had a positive effect towards the elimination of repressive ideas which prevailed earlier towards them. The emergence of parents' associations (such as The Royal Society for Mentally Handicapped Children and Adults - MENCAP), and private efforts, such as Dr. Tom Mutters (2), to the formation of National and International organizations, widened the public acceptance of mentally handicapped people's rights in leading a life, as normal as possible. The change in attitude was demonstrated in the new movement to call the mentally handicapped as people with learning difficulties, or even people with intellectual disability.

The general change in public's attitude towards the mentally handicapped was also demonstrated in a research study conducted for MENCAP in 1982 indicated that the public's emotional responses towards the mentally handicapped were positive and that they have a lot of sympathy for them. About 60% of the public would not be at all concerned if a mentally handicapped child attended the same school as their child.

The study concludes that there is a need to educate the public about the mentally handicapped in two areas:-

a. In the behaviour and needs of the mentally handicapped.
b. The public needs to have certain fears and concern allayed about living side-by-side with the mentally handicapped.

SECTION THREE: NORMALISATION

The concept of normalisation originated in Denmark in the late 1950's (Brown and Smith, 1992). The 1959 Mental Retardation Act defined the aim of the services as being "to create an existence for the mentally retarded as close to normal living conditions as possible" (Bank-Mikkelsen, 1980). This concept has been redefined in 1969 by Nirjie as meaning;

> "making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society". (Brown, 1991).

The underlying principle of this concept was to achieve the full integration of the mentally handicapped, not only in the educational activities, but in all aspects of community life. It also encourages the elimination of large institutions, and replacing them by small units with a homelike atmosphere for those in need of resident care.

Since its inception, normalisation proved to be an influential factor in shaping services provided for people with learning difficulties in Scandinavia, North America, the United Kingdom and Australia (Brown and Smith, 1992). The fundamental aim of this concept was to ensure that people with learning difficulties enjoyed their rights to the same quality of life as non-disabled members of society.

Adams, (1978) provieds the following definitions which is also used by Bank-Mikkelsen (1980):

> "By normalisation we mean acknowledgement of the mentally retarded person and his handicap. Equal status of the handicapped person with other citizens of his country. The right of the handicapped persons to treatment, and to education and training, which must be appropriate for the degree of the handicap, so that maximum potential can be attained".

In 1972, Wolfensberger first proposed a more elaborate definition of normalization, reflecting the interest and work on this concept carried out in North America. He initially defined normalization as "the use of culturally valued means in order to enable people to live culturally valued lives".

Wolfensberger argues that people who are handicapped, sick and old have traditionally been socially devalued. They are seen as not economically useful or productive. Even today people with learning difficulties are still known as "subnormals" (Wolfensberger, 1972). Wolfensberger and Thomas (1983) outline the highest goal of normalization as the creation, support, and defence of valued social roles for people who are at risk of devaluation.

Brandon, and Brandon, (1988) explain the reasons for segregating the handicapped people "it is an almost instinctive social reaction to put distance between oneself and rejected others". The authors highlight the importance of normalisation for such people, a devalued person needs to be integrated into the valued social life of the community, be educated with the non-devalued peers, work in the same places as others, be involved in worship, recreation and shopping.

It is suggested by Thomas (1978) that integration has a number of different elements:

" * Having access to buildings through necessary ramps and wide doors at times when others, who are not handicapped, are using the facilities, with understanding staff to help if necessary;

* Receiving respect, good manners and esteem from others within a society which has a positive image of handicapped people;

* Having the opportunity for a satisfying private life with meaningful relationships;

* Being a citizen with legal status and opportunities for growth, maturity and self-fulfillment;

* Living in a society with structures and forms that assist all those kinds of integration, primarily through generic services".

The principle of normalization is concerned with where a service is going and how it is choosing to get there. The definition of this principle (Obrian, 1981) calls attention to two aspects of any service:

a. What the service does, and the means needed to achieve a service, such as the facilities, the ways in which people are grouped for various purposes, the goals or purposes of the service, the activities, the people who provide the activities and the language used to describe the service.

b. What the service actually achieves for those it serves, such as the social and other skills which people develop, their personal appearance, public image and the quality and variety of the choices in life which people have.

Obrian (1981) considers that the principle of normalisation is a foundation for planning and running services, and it will benefit people with learning difficulties because they are at a risk of being "devalued" by the society, 'Devaluation' happens when a person is seen as being different and the different are socially significant and negatively valued.

The implementation of the normalisation principle requires that people with learning difficulties must experience the community they live with, if they are to learn how to meet their individual needs in socially acceptable way. Social participation requires that people be active participants in a variety of individual and group relationships. Normalisation includes giving people the dignity of risk (Obrian, 1981), which means avoiding attitudes and practices based on the expectation that handicapped people would be endangered by the challenge of living, and therefore, should be completely protected from potential risks.

The term normalisation has now been in use for almost three decades, and its humanistic approach to life is widely regarded in the developed countries as a matter of fact. This principle, however, has its critics, who see three possible contradictions in its application.

> " 1. The principle of normalisation says people with handicaps should be socially accepted and valued. But, isn't it devaluating to handicapped people to try to make them normal?".
>
> 2. "The principle of normalisation says services should use carefully valued means, but if we treat people with handicaps the same as anyone else, they won't be able to develop."
>
> 3. "There is nothing 'normal' about being handicapped. Most 'normal people' and most 'normal' communities do devalue and reject people with handicaps. It doesn't make sense to base a principle on a wish that other people would be more accepting than they are." (Obrian, 1981).

Theoretical principles of normalisation prompted many academic debates on attempts to bring about and maintain, change in human services. Good theory, is essential to good practice, (Brown and Smith 1992). While they agree that the clarity of Wolfensberger's observations provided energy for change and a vision of how things could be, nonetheless, they believe that the time is ripe for a reassessment of the theory.

NOTES:

(1) Queen Elizabeth 1 passed a Poor Law which encouraged parish officials to give some training for employment to blind or crippled children, followed more than two hundred years later by a Poor Law Reform Act 1834, giving similar encouragement to help handicapped young people to obtain education and training for work.

(2) The founder of "LEBENSHILFE" in Germany. He raised an international interest in the mentally handicapped when in spite of all difficulties and hindering laws, he enabled the emigration of mentally handicapped Ukrainian girl named Nadia to the USA. Her story was widely published when the immigration authorities in New York wanted to send her back to Germany again, where she had been living in a hospital for mentally ill and mentally handicapped for so many years.

PART TWO

PART TWO - CHAPTER THREE:

DEVELOPMENT OF SERVICES FOR THE MENTALLY HANDICAPPED IN ENGLAND

INTRODUCTION:

Services for the handicapped in England are provided by a number of statutory (i.e. central and local government) and voluntary bodies. Formal services fall into three main categories:-

a. Medical treatment and rehabilitation
b. Education
c. Community care

This Chapter traces the early development of such services and highlights the main efforts to organize care for the mentally handicapped to date, and outlines the current services provided for them.

EARLY DEVELOPMENT OF SERVICES:

Social services in England have continuously developed since the fourteenth century, when the Poor Law legislation made each parish responsible for looking after its own poor people (Byrne and Padfield, 1990). Until the time of the Industrial Revolution in the mid eighteenth century, there had been little or no established provision of facilities or services for mentally handicapped people. Reliance was placed on the social network of family, friends and neighbours, with any outside help coming from religious organizations (Shanley, 1986).

The changes in work and family life brought about by the Industrial Revolution affected the position of anyone who was dependant on others for economic and social support (Ryan and Thomas, 1991). The strains of trying to cope with the changes

from a rural-based society to an urban society exposed the fragile situation of the mentally handicapped, and prompted the segregation of those who are unable to support themselves from the productive labour force (Shanley, 1986).
The 18th century gave birth to a new social awareness towards the treatment of the "insane". An Act of Parliament was passed in 1774 to regulate private institutions and, after pressure by several societies and individuals, the County Asylums Act was passed in 1808 which paved the way for the development of hospitals to care for those suffering from a mental illness and handicap. At that time, there was no real distinction made between mental handicap and mental illness (Byrne and Padfield, 1990).

The first asylums for the "idiots" were set up in the early nineteenth century, but the growth of such asylums did not correspond with the increase of people who required services of such institutes. During most of the period between 1864 and 1914, there were only six such asylums, accommodating about 2000 "idiots" (Ryan and Thomas, 1991). This represented only a small portion of the 29,452 "idiots" in England and Wales in 1881, found mainly in other public institutions - workhouses and asylums for the insane (Jones, 1972).

Consecutive Acts, (the Lunatics Act 1845, Idiots Act 1886, Lunacy Act 1890 and the Mental Deficiency Act 1913), dealt with multiple aspects of mental handicap, but all of them constituted a different expression of the segregation policy referred to earlier. The 1913 Act introduced compulsory certification for people admitted to institutions as mentally defective. This Act established the basis of a separate and unified service, which would exclude mentally defective people from other welfare and social agencies as well as from the general education system (Ryan and Thomas, 1991).

The Mental Deficiency Act 1913 defined Mental Deficiency as: 'a condition of arrested or incomplete development of mind, existing before the age of 18 years, whether arising from inherent causes, disease or injury'. Under the Act, 'defectives' could be sent to an institutions or placed under guardianship. Prior to the outbreak of World War One realisation began to grow that institutions could not cope with the problem alone, and community care was, "not only cheaper, but more beneficial to the individuals" (Shanley, 1986).

In the early part of the twentieth century, some educational considerations were given to the pupils with IQ's within the 55 to 70 range, and there was support for the view that the school leaving age should be raised to 16 years for such pupils. Children with IQ's of not more than 50, however, were excluded from the schooling system, and considered to be ineducable (Segal, 1984). With the exception of few individual efforts (1), there was no public interest in such children's education or future. In addition, low priorities were given to the training of the staff engaged in the care of such children, and inferior status was accorded to such individuals (Segal, 1984).

Segal (1984) believes that Steiner's ideas and concepts during the early part of the 1900s, and his lectures on curative education during the 1920s helped in creating private interest in the work associated with the maladjusted or delinquent child. The Camphill Schools were founded in 1939, and twenty years later, they were catering for 250 children who were unable to follow the curriculum of an ordinary school because of mental or physical disability.

The immediate post war period witnessed many positive developments towards the improvement of the education and care for handicapped children in general, and the mentally handicapped ones in particular. The 1944 Education Act indicated changes in attitude towards mentally handicapped children. Until then children within the 50-70 IQ range were labelled as "mental defective", athe Act has changed this term to "educationally subnormal" (ESN). This category, which is separated from the, "unsuitable for education" group, formed some 10 percent of the entire school population (Segal, 1984).

Another significant development that occurred towards the end of the 1940s and the first half of the 1950s was the foundation of parents' organizations. These organizations, such as the National Association for Mental Health (NAMH, later MIND), proved to be an effective tool for parents to help their children, influence the public and promote the concept of special education. By the middle of the 1950s, the number of special school places reached 58,000 with a teaching staff of more than 4,000 (Segal, 1984).

DEVELOPMENT OF MEDICAL SERVICES (1950-1990):

In 1948, special hospitals were absorbed into the National Health Service, which made it more difficult to secure the necessary finance required to maintain such hospitals. Eleven years later, the Mental Health Act 1959 allowed the less handicapped to leave the hospitals (Shanley, 1986), resulting in gradual drop in number of adults resident in hospitals. The 1976-1977 report of the Development Team for the Mentally Handicapped stated that there was a drop of 6500 adults resident in hospital over a seven year period (in 1969 adults resident in hospital numbered about 56,000 compared with 49,000 in 1976). In 1974 the National Health Service was reorganized and responsibility for the hospitals was passed to Regional Health Authorities, and the character of the mental handicap hospitals has changed with a greater proportion of highly dependent residents (Ryan and Thomas, 1991).

There was also an encouraging improvement in the number and quality of Child Guidance Clinics and other facilities for maladjusted children. In 1955 Local Educational Authorities was running around 300 Child Guidance Clinics compared to 80 in 1945. There were also 32 boarding special schools, three day special schools, a number of special classes and 45 boarding homes or hostels. Initially run almost single handedly by psychologists, by 1955 most clinics had a team consisting of a psychiatrist, an educationalist and a psychiatric social worker (Segal, 1984).

In response to mounting criticism of conditions in mental handicap hospitals during the 1960's, the government published a policy document in 1971 titled, "Better Services for the Mentally Handicapped", advocating the principle that mentally handicapped people should not be "unnecessarily" segregated from other people. The document envisaged a reduction by half to hospital places by 1991, and a corresponding increase in local authority funded care-hostels and day centres. At the same time it promised upgrading of existing hospitals and advocated an end to old custodial methods and attitudes (Ryan and Thomas, 1991).

A study by Tyne (1978), concluded that different forms of care for mentally handicapped people (such as hospital wards, hospital annexes, hostels, group homes and lodgings), have often failed to provide adequately for even the most basic needs like food, warmth, clothing or sanitation. One of the main conclusions of this study is that although now buildings are brighter and breesier, most of the changes since 1968 have been relatively superficial:

> "The fundamental problems in the organization and funding of our services still remains, and fundamental ideologies about institutions still have not been seriously rethought. For these reasons, some of the most wretched problems still remain and seem likely to continue into the future.

The Jay report, published in 1979, was a significant inquiry, promoting the idea of a radically different programme of service to the mentally handicapped and a new non-medical caring profession. Ryan and Thomas (1991) however, consider that the implementation of such a programme fell short of its original objectives, and instead of taking both financial and administrative steps towards its amounted commitment towards "community care", the government adopted piecemeal changes, with a relatively small scale transfer of resources from the National Health Service to local authorities, and the eventual (unspecified) closure of large hospitals. None the less, they admit that by this action, the argument for community as opposed to hospital care had been won.

In 1981, the government decided to move resources allocated for hospitalising the mentally handicapped from hospitals to community sites, without increasing such resources, a steps considered as a clear commitment by the government to community care (Ryan and Thomas 1991). The main significance of this service was to enable the mentally handicapped people to live with their own families, or in a "supportive local community setting".

In the meantime, the nature of services provided by the National Health Service hospitals has also changed from big ward arrangements to more private and personal dormitories. This approach has been strongly advocated by the National Development Group (1978) in their report "Helping Mentally Handicapped People in Hospital", and resulted in significant changes of the character of such dormitories by recognizing each resident's individuality and needs.

A series of reports in the mid eighties, mostly from the Social Services Select Committee and the Audit Commission, forced community care onto the political agenda. The white paper 'Caring for People', appeared in November 1989, with implementation scheduled for April 1991, followed by the 'National Health Service and Community Care Act 1990'. This act makes further provisions about health authorities, the financing of the practices of medical practitioners and the provision of accomodation and other welfare services by the local authorities. In July 1991, the Department of Health postponed the full implementation of the proposed community care reforms till April 1993.

National Health Service and Community Care Act 1990:

The principle of community care as provided for by the NHS and Community Care Act 1990 is to make local authorities as the main provider of welfare services, rather than the NHS.
Many organizations and individuals welcomed the move away from the medical model of care to community care, and considered that this move will offer a real chance to raise standards of such services, and change the attitudes of people involved in providing them.

MENCAP, one of the main organizations looking after mentally handicapped people in Britain welcomed the proposed reforms and expressed the view that the promise of community care had been a lifeline to the families who look after seventy percent of all handicapped adults. (2)

The NHS, Act 1990 implies a move to shift responsibility for people with learning disabilities to social services, but to retain as much of the capital assets and revenue within the NHS as possible, resulting in the transfer of sums of revenue from health authorities to social services departments (3). In essence, the policy of community care for people with learning disabilities reduces the load on health authorities, while increasing the load on local authorities. There is, however, no evidence that health authorities are raiding the required budgets for other services. Churchill (1992) warns, "Unless arrangements are in place to transfer money, financial provision for this group is likely to reduce, as local authorities are unlikely to be able to make up the difference from their own budgets".

While there has been little disagreement with the principle of community care as provided for by the NHS and Community Care Act 1990, governments, health authorities, care workers and private sector have long been at odds over how to implement it. Following the postponement of the full implementation of the governments proposals until 1993, the Department of Health blamed their decision on local authorities lack of readiness, while local authorities blamed it on the government's desire to minimize poll tax in approach to elections (4).

MENCAP reacted angrily to the news of the postponement and possible shelving of community care reforms. It expressed its concern that the estimated 140,000 people who would have been offered needs assessments and appropriate alternatives to residential care will not have that now. Their only recourse will be to go straight into residential care at government expense. Some private residential homes and nursing homes could go out of business, or decide only to take private payers, because they can no longer afford to run on the low rate of income support they receive (2).

The social security subsidy to independent residential care is a crucial factor in the government's community funding strategy. Hudson, (1991), believes that the desire to curb social security subsidy to independent residential care was probably the single most important imperative behind the new community care legislation. However, he observes that the delay in transferring the care element of social security costs to local authorities until April 1993, has provided health and local authorities with an incentive to transfer institutional care costs for as many people as possible to the social security system. Hudson concludes that this has contributed to the continued boom of private homes which started 1989.

Byrne (1992), anticipates an important role for the private sector in meeting demands for private homes, as new homes will be designed and built for groups of patients with specific needs. Patients with multiple handicaps, physical disabilities and brain injuries will be cared for in units with equipment and staff trained to meet their needs. Byrne argues that, for that foreseeable future, only the private sector will be able to identify local demand, respond quickly and raise the capital for providing additional required places for such patients.

DEVELOPMENT OF EDUCATIONAL SERVICES (1950-1990):

In the early 1950s, the quality of life for children who were mentally handicapped was very poor, as both public and private provision was limited and inadequate. Parents, who were influenced by Steiner's ideas, formed organizations, which in some cases, such as Ravenswood, developed into a form of community to accommodate the mentally handicapped and look after them (Segal, 1984).

Societies such as National Association for Mental Health (NAMH), the Royal Society for Mentally Handicapped Children and Adults (MENCAP) and the National Society for Mentally Handicapped Children (NSCMHC) were supporting the establishment of an independent education system for children who had been excluded from mainstream education. By the beginning of the 1960s this movement gathered momentum and such societies witnessed a great deal of success. The NSMHC for instance had some 20,000 members in 260 local societies throughout England and Wales, and was offering a range of advisory services along with training centres, holiday schemes and youth clubs (Segal, 1984).

In 1974, the Government appointed a special committee of enquiry to investigate a report upon the needs of children with a physical or mental handicap. The Committee first met in September of that year and its last meeting was in March 1978. Its terms of reference were, 'to review educational provision in England, Scotland and Wales for children and young people handicapped by disabilities of body or mind, taking account of the medical aspects of their needs, together with arrangements to prepare them for entry into employment; to consider the most effective use of resources for these purposes; and to make recommendations'. The findings of this Committee commonly known as the Warnock Report, have been contained in a report entitled "Report of the Committee of Enquiry into the Education of Handicapped Children and Young People", which was published in May 1978.

The "Warnock Report" recommended the introduction of a new system of special education based on the special educational needs of the child rather than basing it on specific categories of handicap. The report suggested that about twenty per cent of children will require special education during their school lives. These include not just the physically or mentally handicapped children but also those who may be suffering from emotional or behavioural as well as learning difficulties. The recommendations of the Warnock Report formed the basis of the Education Act of 1981 which came into effect on 1 April 1983 and greatly altered previous legislation concerning the education of physically and mentally handicapped children and young people. It has also shaped the framework of current system for special education.

The responsibility for identifying the children who may require special education now rests with the local education authorities (LEAs), each responsible for its own specific area of the UK. Each child who is considered to need special education is assessed by his or her LEA, which has to take into account medical, psychological, educational and any other relevant factors.

Under the new arrangements special educational facilities are being provided in a variety of different environments, for example; in special schools, in special units attached to primary/secondary schools, in special classes in day/boarding schools, hospitals or in ordinary classrooms of existing schools where the child is educated alongside pupils who do not suffer from any form of disability.

In cases where the LEA is unable to make provision for its own special schools, it uses special schools which are run by voluntary organizations or independent schools. In 1982 there were some 1,644 such special schools (both day and boarding) run by LEA's and voluntary organizations in this way in England, Wales and Northern Ireland (Segal, 1984). Such special schools have an undoubted advantage over ordinary schools because they enable classes to be smaller so that there are fewer pupils to each teacher. In this way the child is able to receive more individual attention from the teacher. In addition to this, the classes can also provide physiotherapy, speech therapy or any other special facility which may be required.

Currently, education for the mentally handicapped children is provided at the pre-school stage and the schooling stage. Play groups and nursery schools are provided, either by voluntary associations and parent groups or by the Education Department. Play groups usually cater for children between the ages of two and half and five years of age. Mentally handicapped children attend either the conventional play-groups or play-groups specially organized to cater for their needs.In England and Wales there are two types of special schools for the mentally handicapped:-

1. Schools for the educationally subnormal (severe) (ESNS).
2. Schools for the educationally subnormal (mild) (ESNM).

The compulsory period for schooling in the UK is from the age of five to sixteen, but it is usual for children who have special educational needs to stay on at school after the age of sixteen. In the case of physically handicapped students a few institutions provide further education (beyond the age of sixteen), but it is not unusual for handicapped students to go on to attend ordinary colleges of further and higher education.

COMMUNITY SERVICES:

There are other services provided for the mentally handicapped by the community, other than health and education, such as:

a. Residential services
b. Non-residential provisions
c. Financial provisions

A. Residential Services:

These services are provided outside National Health Service Hospitals, in one of the following categories (Shanley, 1986):

a. Children's Homes: Either in big groups of 20-30 children or in smaller groups, where real living conditions can be accomplished.

b. Fostering: Children of all ages benefit from this scheme, which can be either on short term or long-term basis. In some cases mentally handicapped children were totally "absorbed" into the surrogate family.

c. Hostels: Hostels provide residential facilities of varying degrees of mental handicap. Hostels provide self contained living units, some are staffed and others are un-staffed.

d. Group homes: These are mostly separated by the local authority. This system allows for a group of three to five mentally handicapped adults to live in an ordinary setting, a house.

e. Sheltered housing: This type of accommodations (usually provided for the more able or ideally competent of the mentally handicapped), consists of a group of houses, adjacent to each other and are often supervised by a warden, either resident or living nearby.

f. Lodgings: In this scheme, local authority pays local boarding houses, hostels and private householders to provide full or part board for selected mentally handicapped people.

g. Nursing and rest homes: Some of the elderly mentally handicapped are being catered for in either nursing or rest homes, and are receiving the same care as offered to the other elderly of the society.

B. Non-Residential Provision:

a. Adults Training Centre (ATC): These Centres are geared to provide the adult mentally handicapped with all aspects of social education.

b. Sheltered Workshops: This facility provides an area of experience that allows handicapped people to contribute to a manufacturing process and hence gaining a sense of achievement. Remuneration in such facilities is not based on production level, but for handicapped person's effort and enthusiasm.

c. Others: There are other self-help groups such as parents' groups, that are usually affiliated to some societies or organizations. Their activities vary from arranging play groups, swimming activities, sponsoring schemes (such as the Gateway Award Scheme, which is similar to the Duke of Edinburgh Award Scheme), and 'Enclosed schemes', which provide supervised special employment for small groups of mentally handicapped people.

C. Financial Provisions:

There are a number of financial provisions for the mentally handicapped, made available by government sources and special local provisions such as pensions (non-contributory invalidity pension - NCIP), allowance (mobility and attendance), funds (family fund) and other supplementary benefits and allowances such as family income supplement, transport schemes and free medical prescriptions.

VOLUNTARY SERVICES:

Voluntary agencies were formed by parents of mentally handicapped children and their supporters in order to complement services already provided by the National Health Service and local authorities. Their activities aim at achieving the following objectives:-

a. Provide residential facilities of different types;
b. Act as pressure groups working on behalf of the mentally handicapped;
c. Offer a range of personal services such as counselling and advisory service to parents;
d. Ensure the continuation of taking a personal interest in the mentally handicapped after the parents have died.

Various voluntary and self-help groups such as Mencap (see Chapter Four), National Association for Mental Health (NAMH) Mind, National Society for Mentally Handicapped Children, Dr. Barnardo's, the Cheshire Foundation, Camphill schools and village communities, provide different types of services and support to mentally handicapped people and their families. Primarily, these organizations provide a variety of residential facilities in different parts of the UK. Such facilities range from houses in ordinary housing estates, to village communities (Camphill Houses and CARE). Home Farm Trust, which was founded in 1962 by a group of parents, offer a "care for life" service by providing residential homes for mentally handicapped people from the age of 16 years upwards.

Other activities of voluntary groups include Trusteeship Schemes, which help reduce the anxiety of parents for a long term, holiday houses and residential courses for mentally handicapped teenagers. They also provide parents with practical advice and guidance on the training of mentally handicapped children and teenagers.

During the last 20 years, new pressure groups were formed, as a result of disagreement with government policies and provisions for the mentally handicapped. CAMPAIGNING FOR MENTALLY HANDICAPPED (CMH), began in 1971 as a result of the government White Paper, "Better Services for the Mentally Handicapped" published in that year. Although recommending an increase in community provision for people with learning difficulties, the White Paper envisaged a continuing role for the mental handicap hospitals, whereas CMH strongly advocated the closure of such hospitals.

The emergence of such pressure groups added another dimension to the voluntary groups work. Groups such as CMH produced series of inquiries and reports on all areas of life affecting mentally handicapped people, as well as radically criticizing government policies. Compared to the long established charities and voluntary organizations such as MENCAP (Chapter Four), CMH's objectives are:-

- Campaigning for an end to segregated services;
- Showing how people with learning difficulties can achieve full and valued lives in the community;
- Supporting participation and self-advocacy;
- Working for greater public acceptance;
- Supporting work at national and local levels.

In spite of their continuous financial, legal and bureaucratic difficulties, voluntary organizations continue to play a significant role in supporting the physical, educational and occupational needs of the mentally handicapped persons and their families.

NOTES:

(1) Such as Jessie E. Thomas the author of "New Hope for the Handicapped, A Teacher's Testament", and who had been awarded an MBE in 1940 for services to special education.

(2) The Health Service Journal, 19th July, 1990.

(3) The Health Service Journal, 7th May, 1992.

(4) The Health Service Journal, 1st April, 1993.

PART TWO - CHAPTER FOUR:

THE ROYAL SOCIETY FOR MENTALLY HANDICAPPED CHILDREN AND ADULTS - MENCAP

INTRODUCTION:

The previous chapter included a general description of the role played by parents associations and individual societies, and their contributions towards the advancement of the cause of mentally handicapped people all aspects of care, (health, education and social welfare).

The Royal Society for Mentally Handicapped children and adults is one of the most active societies of its kind, and provides many different services to the mentally handicapped people and their families. This chapter describes in more detail, how this association has developed, and the full scope of services it provides.

In 1946 MENCAP started as an association formed by parents of mentally handicapped children in order to persuade authorities to provide them with the services they needed. This association was launched by Judy Fryd who herself is a mother of a mentally handicapped child, and called it "The Association of Parents of Backward Children". At the same time, she started a newsletter which she edited herself and was circulated to all members.

The association membership grew very quickly, and parents from all over the country formed local groups where they raised money and worked towards gaining concessions for them in social security and family allowances (Shennan, 1980). Education was on the top of the Society's agenda, and Judy Fryd worked passionately to prove that no child was incapable of being educated. In 1955 the Association of Parents of Backward Children changed its title to "The National Society for Mentally Handicapped Children", and more recently, it has become "The Royal Society for Mentally Handicapped Children and Adults". This society, which is now generally known as MENCAP has grown to become a nation-wide organization, with more than 55,000 members, most of whom are parents and friends of the mentally handicapped (Mencap Information Sheet, 1987).

Services provided by MENCAP:

MENCAP provides a wide range of services for mentally handicapped people through its national centre in London and its 500 local societies throughout the country. These services are extended to the families and people involved in such activities through many channels and means such as campaigning, education, awareness, local societies, residential homes and training centres. MENCAP also organizes a work preparation and job-placement scheme in addition to helping parents in identifying suitable holiday location (Constant, 1985).

A. Campaigning:

MENCAP's legal department provides services to MENCAP's local societies, people with learning disability, and their families. MENCAP's campaigning activities extend into Westminster and Whitehall too. MENCAP employs a Parliamentary officer whose main function is to promote the needs of people with learning disabilities at Parties Conferences, and lobbying Members of Parliament in order to achieve MENCAP's objectives.

B. Education:

MENCAP runs training centres for professionals and voluntary helpers who work with mentally handicapped people in order to meet their "special educational needs". This service became necessary as all children, however severely handicapped, became in 1971 entitled by law to education. MENCAP also runs residential colleges where students spend two years after school, going through a variety of activities and disciplines, leading to noticeable development in their personal and social skills.

C. Awareness:

MENCAP's main objective in this respect is to make sure that everyone in Britain is aware of people with a learning disability, their potential and their needs. High on its agenda is to explain the difference between learning disability and mental illness, and to educate school children regarding the existence of people with special needs in the society.

D. Local Societies:

These are spread all over the UK, and vary in sizes from groups of ten to more than 500 members. Local societies have many functions, but their main advantage is to bring parents of mentally handicapped children together with other groups of volunteers and helper thus reducing the isolation that was experienced in the early years by parents, and particularly mothers with handicapped children. Services provided by local societies ranges from providing a personal advisory service for parents to forming playgroup for children. They also provide representation for mentally handicapped people with health and educational authorities.

E. Residential homes:

It is now generally accepted that all mentally handicapped persons, even if they have a physical disability, will benefit greatly if they live in a homely environment of a residential home. Therefore, MENCAP provides homes for mentally handicapped people, which is carefully furnished so that they look like normal family homes. MENCAP also created a "Homes Foundation" to provide residential accommodation for mentally handicap adults. This is to meet a particular anxiety of older parents, regarding who will care for their child when they themselves are too old or when they die.

F. Training Centres:

When they leave school, most young people with learning disability need to be trained to live a normal life. Those who are able, are trained in special MENCAP training centres to learn handicrafts or jobs like packing, laundry, and operating light machinery to prepare them for employment. MENCAP has other training centres. For instance, Pengwen Hall Residential Centre Wales was bought in 1966 for school-leavers. The emphasis in this facility is on training mentally handicapped youngsters to live with the minimum possible support in ordinary house. They learn to look after themselves in every way, taking decisions and facing up to the discipline of everyday life in a community. Another example is Lufton Manor, a residential training unit is Somerset, where young people of sixteen and over train in agriculture, horticulture and estate maintenance in a sixteen hectare area of farmland, gardens and workshops.

G. Job Placement:

MENCAP organizes a scheme for work-preparation and job placement, designed to encourage employers to take on mentally handicapped people. Employers frequently found that mentally handicapped people can make good employees and many of them are capable. Through this scheme, those mentally handicapped people who are considered suitable for employment are assessed and trained, then placed with a firm for a three months probationary period. During this time the employer is offered a training grant and an allowance is also offered to an employee who volunteers to act as "foster worker" until the new comer has been officially taken.

H. Financial Resources:

MENCAP relies heavily upon voluntary contributions for a major part of its income. Fund raising is a highly competitive business in the UK, and therefore, MENCAP operates a full-time Appeals Department, run by professional fund-raising staff. This department plans the fund-raising programme, bringing in an annual income of over 750,000 (Constant, 1985). Activities includes house-to-house collection schemes; prize lotteries; art exhibitions; balls and charity concerts; gala first nights; Derby draws; mail appeals; box collection schemes; sponsored activities; marathons; flag days, and sales promotions.

One of the main sources of income to MENCAP results from the sale of cards and gifts all over the country. Local societies achieved sales of 1,633,000 for 1991 cards (Mencap News, 1992). These show a wide range of the society's products, many made by mentally handicapped people themselves. This form of self-help is an important way of encouraging mentally handicapped people towards independence and at the same time showing the public how determined they are to try to be self-supporting.

Regular fund-raising parties are also organized by a number of "support groups" and make substantial donations out of the proceeds. MENCAP also relies on local societies to raise money for projects in their own areas. Advice on fund-raising methods is given to local societies by Regional Appeals offices, employed by MENCAP for this purposes and to help them organize their own local events (Constant, 1985). The MENCAP headquarters in London has a large sales area which includes a bookshop catering for parents of mentally handicapped people and for professionals in the field. Teaching aids and learning materials are also available there.

PART TWO - CHAPTER FIVE:
WAVERLEY SPECIAL SCHOOL, ENFIELD

Introduction:

Since the 1971 Education Act came into force, placing the responsibility of the schooling of all mentally handicapped children with the local education authority, special schools for mentally handicapped children started to exist and spread throughout the UK. The advantages and disadvantages of special schools for the mentally handicapped were outlined in Chapter Two of this work. Special schools, continued to spread with the main objective of providing the mentally handicapped children with the specific form of education they require, rather than to isolate them.

Due to financial restrictions, the provision of purpose built special schools in the UK has not progressed at the same rate as it did in other parts of Europe like Germany or Sweden. However, some conscious efforts were made to improve the standard of existing facilities providing such service.

Waverley Special School is considered to be the English equivalent of modern schools in Germany, and was selected to demonstrate that when an old school building is properly refurbished and reequipped, it can provide a specialised curriculum within an appropriately organised facility. The original school building was built at the turn of the century, but has been reequipped and was opened in 1971, when responsibility for the Junior Training Centre for severely subnormal children in Waverly Road was transferred from the Department of Health to the Department of Education and Science.

Facilities and Curriculum:

Waverley School is a day school that caters for pupils with severe learning difficulties whose ages range from two to 19. Some pupils have additional difficulties which may include visual, hearing and physical impairments. The school can accommodate up to 120 pupils (a total of 92 children with approximately 40 teachers and assistants) and is divided into four departments: nursery/reception, infant/junior, senior and 16+. Each department has three classes enabling pupils to be taught in small groups with a high staffing ratio. The school accommodates an age range between two and 18 years in twelve separate classrooms with a capacity of 10 students in each classroom.

The curriculum is delivered in a variety of ways appropriate to the child's needs and by a wide range of people: classroom staff, specialist teachers within the school, parents and outside agencies such as physiotherapist and speech therapists. Teamwork is of paramount importance.

The ultimate aim of the school is that each child shall maximise his or her potential and therefore achieve as great a sense of independence as possible. All pupils at Waverley have full access to their environment and learning experiences are delivered in motivating, challenging and age-appropriate situations.

Aims, objectives and the curriculum offered ensure progression on the pupils throughout the school. While each department reflects the general philosophy of the school it also has an individual approach appropriate to the age and need of its pupils. In the nursery, pupils have access to a wide range of experiences that would be available to all children of this age, whatever their abilities. these early experiences are built on and developed throughout the school and, when they enter the 16 and above department, additional emphasis is placed on independence and leisure skills, personal development and self-advocacy.

The excellent facilities at Waverley provide many opportunities for exciting curricular activities, creating a busy atmosphere and offering stimulation and challenge. This in turn motivates and helps the child to achieve, thereby gaining confidence, self-esteem and a sense of worth. Emphasis is always placed on the individual child.

The following therapists are part of the teaching staff.

(a) Speech Therapist
(b) Physiotherapist
(c) Occupational therapist
(d) Music therapist

All social workers are employed directly by the local authority and work away from the centre. Early Intervention is the responsibility of three departments of the local authority, i.e. Health Dept., Social Welfare Dept., and the Education Dept., and any problem children are referred back to the centre by any of these groups for assessment and possible future schooling. All home liaison work is carried out at the parent's home rather than within the centre and therefore no facilities are provided for these facilities within the centre. A Consultant paediatrician is available for referral purposes by the centre.

There is a strong relationship between the general public and the centre's activities in this matter. Wherever possible the children are taken into the community for practical training in terms of integrating within the community and it is only when the children are taken on social outings that they experience steps, lifts, escalators, etc., as there is no change in levels in the school.

The school has an open door policy within the junior classes where parents can attend the classes and assist in the teaching at any time. This policy did not apply to the senior level of the school as they considered it important that the older children have their independence and it is up to the children to decide whether the parents can attend on requested days. The school holds coffee mornings for various parents groups and there is a dedicated room for the parents in which they have their own notice board which has child minding agencies, etc. The room is a catalyst in the development of relationships between parents of handicapped children and is a useful facility within the centre.

Special Arrangements in the Building:

The building is developed around several external courtyards which are landscaped with water features. The courtyards have been developed to encourage the movement of children through the spaces and get them used to touching water, rocks and other outdoor objects, (See Diagram 5.1).

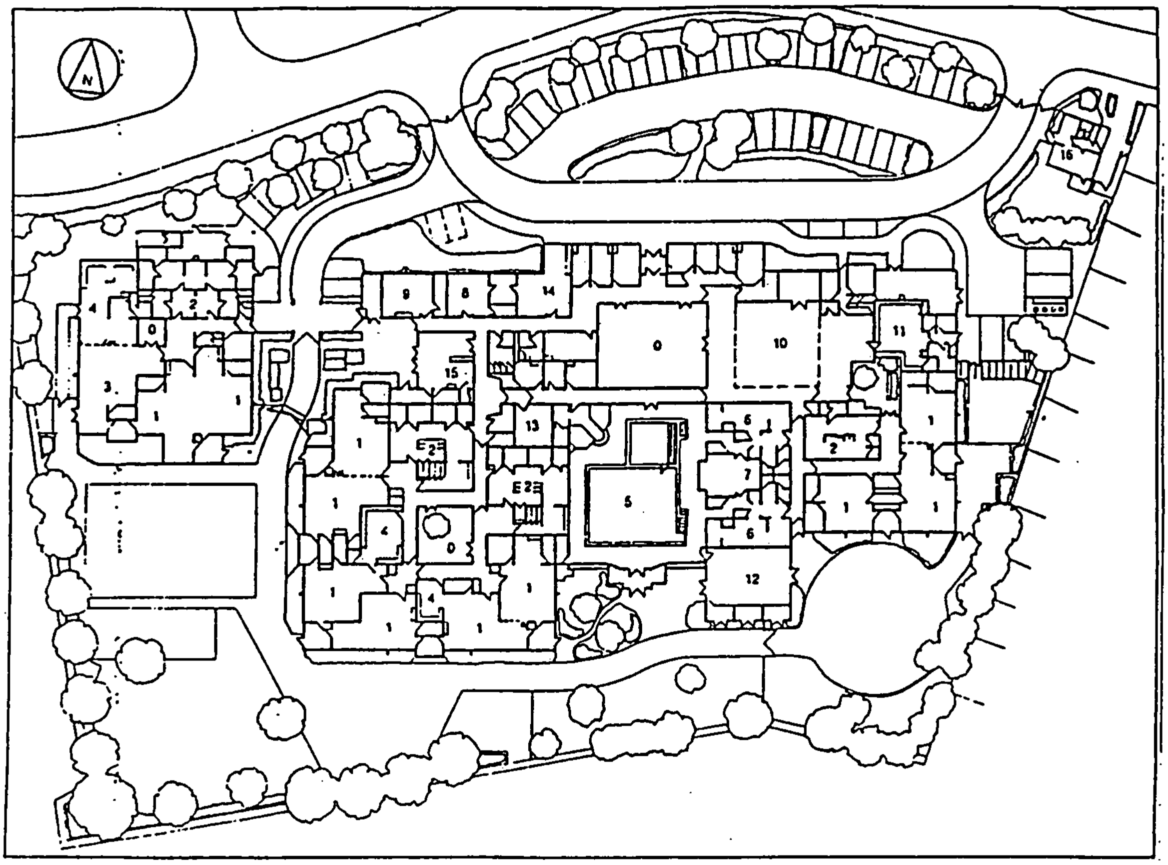
All doors have a double handle opening device which meant that children could not enter the classrooms without the teaching assisting. This facility was required because there a number of mentally disturbed children who wander and it was considered that this was the most appropriate way of discreetly fitting locks to the classrooms. Each classroom is fitted with a telephone system and that provides intercommunication between classrooms and administration as well as external lines. It also has a small enclosed external area for use during inclement weather as well as a garden.

Toilet facilities particularly for the junior school are extremely well developed and have a number of features which were considered to be ideal. In particular, the total area of the toilets is extensive with separate areas for wash down facilities for incontinent children including Arjo wash tables and nappy changing tables. Above the nappy changing tables, are a series of shelves and baskets with each child's name on it in which their own nappies, etc., were stored. Each family is responsible for providing suitable nappies and change of clothes for children with such difficulties. Also included within the bathroom areas are large magnetic notice boards which contained details of each child using the toilet facility with particular reference to the number of times the toilets were used by each child. This monitoring process assists the staff to identify any problems the children may encounter in terms of regularity or change of pattern.

Within the therapy pool area there is a lifting hoist/swing with a concealed track which runs the full length of the room from the end of the therapy pool through to the washdown facility area.

The school is provided with two craft rooms, one dedicated to wet clay type material and pottery making and the other to paper and light timber work. Adjacent to the craft rooms are store rooms. There are a series of home economics rooms fitted with kitchen and laundry equipment within each department. Generally these are located between classrooms and are designed to suit the age of the children. As each age group became older, the sophistication of the equipment increased as well as the room size. Generally work benches, etc., are at normal height but electronically and mutually adjusted cooking equipment, servery benches, etc., are provided.

The senior school is provided with a full working residential unit including a living room, kitchen, bathroom, bedroom, etc.. This living quarter allows the older children to experience the full range of domestic duties. In the future the children would be actively encouraged to stay overnight to experience the full range of activities when living alone. Generally this area is minimally supervised and is considered the personal domain of the senior students. Adjacent to the living area are two large home science kitchens with main dining facility which enables the senior children to eat in their own environment as well as prepare the meals. All home science areas are fitted with gas and electric cooking equipment as well as microwaves. The main living area for the senior students is fitted with carpets to closely simulate the house environment.



Key

0	Courtyard
1	Classroom
2	Toilet area
3	Social living
4	Home economics
5	Pool
6	Changing
7	Hydrotherapy
8	Library
9	Technology
10	Multipurpose hall
11	Kitchen
12	Plant
13	Soft play
14	Staff room
15	Craft room
16	Caretaker's house

Diagram 5.1 - GENERAL PLAN

PART THREE

PART THREE - CHAPTER SIX:
SERVICES FOR THE MENTALLY HANDICAPPED IN GERMANY:

DEVELOPMENT AND SCOPE OF SERVICES:

In the Post War period, i.e. after 1945, special attention has been given to the people with mental handicap in Germany. The feeling of guilt towards the way these people were treated during the Nazi reign was an extra motive to organize help and assistance at all levels.

The system serving the handicapped in Germany nowadays has been developed in such a way that state resources and private initiative complement each. Government welfare agencies (state and community) work together with the voluntary welfare associations in order to provide different types of services for all handicapped people in Germany.

Federal Social Welfare Law, determines that the government social welfare departments should create no facilities of their own for handicapped persons, in as far as these can be created by the voluntary welfare associations. However, the running costs of the necessary facilities must be taken over by the competent social welfare department, and the investment costs of such facilities are paid for in the majority (about 80%) by public money. A variety of privately administered services for the handicapped has been developed on the basis of these principles. Most of the residential facilities and the community 'day-care' facilities for moderately, severely and profoundly mentally handicapped children, adolescents and adults are run by private associations. Whereas the LEBENSHILFE, (the German association for the mentally handicapped) as an association of parents and friends of the mentally handicapped, runs most of the day facilities, church associations (protestant and catholic) run most of the residential facilities, (Mutters, 1987).

In Germany there is no system of compulsory registration of handicapped persons. Parents are, however, encouraged to take a handicapped child to a doctor or to the health authority. Para-medical staff, educators and social workers are required to remind parents of this duty. In case parents refuse to consult a doctor, the health authority must then be notified.

A system of early detection was introduced in 1971 when screening of all children or only high risk ones was provided by law in all states of the Federal Republic of Germany. These statutory routine examinations are voluntary and not legally binding. This new scheme of early detection takes the form of eight tests, the results of which are noted in a child's test booklet (laid out as a kind of 'check-list system'). These prophylactic measures are financed by the statutory Health Insurance. In the course of these controlled, prophylactic tests the doctor examines the child according to an exact procedure laid down for each age-group. In this way his attention is drawn to the risks especially prevalent in the specific age group.

Another important factor in these exactly programmed tests is that they are carried out to detect specific defects which only become noticeable during a particular period in the course of a child's development. The advantages of this 'check-list system' are that all the tests can be recorded in precise detail. An exact schedule of tests can be arranged whereby the doctor only needs to tick off the results. The mother then finds an exact explanation for each test in the booklet, and it gives exact particulars of the health and development of her child at any time. Every doctor who is to carry out further tests will have the results of earlier tests at hand. The tests are carried out as follows, (Mutters, 1987):

a. the first, one at birth
b. the second, one on the 3rd to 10th day of life

c. the third, one in the 4th to 6th week of life
d. the fourth, one in the 3rd to the 4th month
e. the fifth, in the 6th to the 7th month
f. the sixth, in the 10th to the 12th month
g. the seventh, in the 21st to the 24th month
h. the eight, between the age of 3.5 and 4 years.

The diagnostic work is done in special diagnosis centres or clinics, so-called "early educators" or through a 'home visit'. They guide the mother in all questions of daily care and show her how she can initiate activities and stimulate her handicapped baby. Perception, motor abilities and speech are stimulated and developed. Later in the play-group the social responses of the child are developed step by step, thus also preparing the child for the 'nursery group'. A doctor (in most cases a pediatrician), physiotherapist, speech-therapist, social worker and psychologist are also members of these "early help" teams. Group talks with mothers, courses for parents and the organization of baby-sitter services and recreation possibilities for mothers are among the 'early help' facilities, (Lebenshilfe, 1969).

As from the age of three the child can enter a special nursery where each group consists of a maximum of six children. Special nurseries may be located near an ordinary nursery or near a school for mentally handicapped children. Efforts to fully integrate handicapped children into general kindergartens or to train and treat them in remedial educational groups of their own in facilities for non-handicapped children has progressively increased. One of the reasons for this is the considerable fall in the birth-rate and the resulting lack of children in general kindergartens.

Schools for the mentally handicapped (those with IQ approx. 60 and below) in most of the German states are administered by the communities (1). In some states, e.g. Bavaria, schools also may be run by private associations as 'LEBENSHILFE' (Appendix 4). In that case, however, the obligation to finance building and maintenance still rests with the state authority. The Education Acts of all states provide for compulsory school education for all children from 6 - 15 years of age. For mentally handicapped children this period can be extended for a certain number of years, in some cases, even until the age of 25.

Schools for the mentally handicapped have three grades and the classes or groups which generally have an average of six to eight children. Mentally handicapped children are admitted to schools according to their age, starting at six or seven years old. Generally, it takes children nine years to complete this phase, divided to three stages, three years of low classes, three years of middle classes and three years of higher classes, (Mutters, 1987).

Heads of schools for the mentally handicapped, as well as a rapidly growing number of teachers in these schools, have either completed - in addition to their general teacher training - a two-year training course in special education (full study) or finished a four or five-year basic training in special education specializing in one or two forms of handicap (this specialization takes place after two years of training). Assistants in these schools must have completed a two-year in-service training course for educational duties in facilities for the mentally handicapped. Physiotherapist, speech-therapist, teachers in rhythmics and occupational therapists are also usually found on the staff of schools for the mentally handicapped.

Schools for the mentally handicapped are all-day schools, in contrast to the general schools, which, in Germany, are half-day schools. For this reason alone the integration of a school for the mentally handicapped into a normal school causes difficulties. More and more schools for non-handicapped children, however, at present in 40 cities - are opening classes for both non-handicapped and handicapped children. Adolescents leaving schools for the mentally handicapped generally enter a sheltered workshop (at present there are 400 sheltered workshops employing nearly 70,000 mentally handicapped persons, (Mutters, 1987).

The transition from school to work takes place partly in the last class of the school, partly in the sheltered workshop. In the later case there are two stages of work preparation:

a. The initial stage mainly serves orientation, habituation and individual pre-training of the handicapped lasting up to three months.

b. The training stage lasting up to three years providing the trainee with knowledge and skills for a wide range of techniques and work activities, such as assembling and mounting, operating machines, handling materials, domestic and other services, agricultural and animal husbandry.

After completion of this training stage the handicapped person is provided in the sheltered workshop with work most suited to his abilities and inclinations. The sheltered workshop must also offer programmes for the more severely mentally handicapped. Sport and adult education are included in the programme for both groups, (Lebenshilfe, 1990).

The rights of mentally handicapped persons as proclaimed by the United Nations in 1971, have a legal base in various German Laws. In as far as general laws do not account for the special needs of handicapped persons, provisions to meet these needs have been made in additional legislation applying to the handicapped - especially in the field of vocational and social integration.

Many new activities have been started since then, especially as a result of improved legislation and additional funding. A network of modern and efficient rehabilitation facilities, which includes those for the mentally handicapped, has been extended over the whole field of aid for the disabled. A new Act applying to the severely handicapped (passed in 1974), extended the provisions designed to ensure the vocational and social integration of the severely handicapped to all severely disabled, irrespective of the type and origin of their disabilities, (Mutters, 1987). In accordance with this law, employers, both private and public, with a minimum of 16 employees, are obliged to occupy a 6% quota of severely handicapped persons. Provision is made for the payment of a monthly compensatory contribution by the employers for each unfilled vacancy in the quota. The proceeds of these contributions are used primarily for the provision of jobs suitable for the disabled.

A law relating to the social insurance of the disabled, which came into force in 1975, initiated compulsory social insurance (disablement and retirement insurance and health insurance) for disabled persons working in sheltered workshops, and in homes and institutions, as well as for disabled trainees in vocational training centres.

In 1975, an information campaign was launched by the government enforcing that everyone, including the disabled, has his part to play in the community. Focal points of the campaign are advertisements in magazines and television spots, as well as brochures imparting factual information about the different groups of handicapped persons. In addition, detailed guidelines are given to assist initiatives by lay persons and to encourage the formation of new private groups.

In the meantime, public awareness regarding the mentally handicapped people was largely increased through the efforts of private societies and devoted individuals such as Dr. Tom Mutters, who played a major part in promoting public interest through his lectures, publications and numerous other activities.

Dr. Mutters (1) was one of three presidents of the "Aktion Sorgenkind", (Action Problem Child) which started 1964. Through his initiative and efforts, this association started with the help of one of the Television Corporations in Germany (Aktion Sorgenkind), an association of all volunteer organizations for the help of handicapped children in association with this television corporation are working together, and so far collected over one billion Deutch Mark for setting up facilities of all kinds for handicapped children.

In Germany, all efforts for handicapped people e.g. for blind, deaf, spastics, epileptics and other groups are coordinated through one common organization: "Hilfe fur Behinderte" (Help for the Handicapped) with its secretariate in Dusseldorf. The main function of this organization is to coordinate common tasks like information, legal measures, help for the multiple handicapped, etc., and to make the work for all groups of handicapped still more effective.

For the purpose of this study, examples of two different types of facilities provided for the mentally handicapped people in Germany will be described:-

a. Religious organization providing full services to the mentally handicapped in a community setting comprising all ages - Stetten

b. State day school for mentally handicapped children - Senden.

Lebenshilfe, is considered to be one of the major organizations in Germany in the field of providing services to the mentally handicapped and their families. A general description of this organization and its activities is included in Appendix 4.

NOTES:

(1) The word "Community" or "Gemeinde" in German, is a special term used to describe a group of people selected from the local community to form a body which has administrative and financial powers related to the local affairs of the Community "villages, or group of villages" such as education, health, municipal services, etc..

(2) Dr. Tom Mutters, previously mentioned in Chapter Two is one of the most prominent personalities in the field of care for mentally handicapped people in Germany and Europe as well. An educationalist by profession, he founded in 1958 the National Association for the Mentally Handicapped 'LEBENSHILFE' in Germany and the International League of Societies for Mentally Handicapped Persons in 1960. A founder of "Aktion Sorgenkind" (Union of Volunteer Welfare Organizations and Television Corporation ZDF in 1964. He became the first president of the European Association of Societies for Persons with Mental Handicap in 1988.

PART THREE - CHAPTER SEVEN:
ANSTALT STETTEN:

Stetten was selected as an example of services provided for a large community of handicapped people by a non-profit making religious organization in Germany. The high standard of care and management found in this institution demonstrate the devotion and effort required to organise medical, educational and social services to a group of mentally handicapped people. The following is a general description of the facilities and services provided at this institution.

The 'Anstalt Stetten' was founded as a Christian institution by Georg Friedrich Muller on 21st of May 1849. His work started in some rented rooms which were part of a small castle near Vaihingen/Enz (some 60 km away from Stetten). At the time, he worked with just two mentally disabled children, and certainly could not foresee the outcome of his "little missionary work" some 141 years later - a larger institution which is preoccupied with providing adequate help for more than 2000 disabled people of all ages, (Shurr, 1990).

Since 1863 the institution has been located in "Stetten im Remstal", part of the larger community of Kernen im Ramstal. (near Stuttgart). It was from here that the 'Anstalt', - as the institution is also called, - developed its different branches and spread all over the surrounding area. Today, several places of training for the learning disabled young people and mentally are part of the 'Anstalt', too.

The main objective of the "Anstalt" is to provide an environment where mentally handicapped people can lead a semi-normal life, and to create a place where the residents can enjoy living, (Shurr, 1990). Hence, in addition to educational, training and therapeutical facilities, accommodation is provided in such a way that all residents live in small, family-like residential groups of four, six, eight or ten people. Accommodation is provided in a variety of types and sizes (single room, double room and triple room).

Since 1968, school attendance in Germany for the mentally handicapped up to the age of 24 is compulsory. In Stetten, right from the start teaching and giving professional training to disabled people has been an integral part of the Anstalt's activities. This became necessary, as for some going to school means learning how to deal with numbers, letters, and words, whereas others are preoccupied with learning how to eat on their own or how to visually identify something. After school, further education takes place in the therapeutical sections, where general education for the severely disabled who cannot go to work on a regular basis continues in the 'Heilpadagogische Forderung and is supplemented by developing the clients' specific talents, e.g. painting in creative workshop (Kreative Werkstatt). Some of them are also given the chance of improving their overall abilities on horseback in the (Riding therapy) 'Reitherapie' or by receiving physiotherapeutical treatment. It is considered that both the school and the therapeutical sections provide specific spheres of learning and gaining experiences to enable every individual to develop his ability towards independence.

Another important aspect of services for the disabled offered by the "Anstalt" is to provide job opportunities. The intention is to provide a challenging and responsible task which helps develope confidence in the mentally handicapped. Like others the mentally handicapped show a need to achieve something and have their own income. Many of these employed in the 'Workshops for the Disabled' and in the catering units are, like all other workforce, registered with the social insurance system and earn a wage which they can freely spend. Job opportunities are offered in the following departments:

1. in the "Factory", assembling and packing industrial products;
2. in the pottery workshop;
3. in the carpentry workshop making shelves and doll's houses;
4. in the canteen kitchen;
5. in the weaving section;
6. in the stamp centre;
7. or even in the fleet of vehicles, co-drivers.

Stetten, occupies an approximate area of 79 acres and comprises the following facilities, (see Diagram 7.1):

Administration Building:
Was built 1892, but used as an administration and management centre for the whole community from 1986. It is named the Landenbergerhaus, after Johannes Landenberger, the director of the institution from 1860 till 1877. He is considered one of the pioneers in establishing care and treatment for the mentally handicapped.

Central Building for food supplies and preparation:
Built in 1969, complete with a kitchen, bakery, butchery shop, a dinning hall for people working in the institution, a conference room, a grocery and a shop to sell material produced in the workshops of the institution. This shop is also used as a place to train the mentally handicapped how to select and buy things by themselves. The kitchen produces 1800 meals daily, and more than 450 people (workers and residents) are employed in this Centre.

The School (Ludwig - Schlaich - Schule:
This is a teachers training school on social and special education. It was named after the evangelican minister Dr. Ludwig Schlaich, who was the director of the institution from 1930 to 1967, and founded a course in behaviour modification. 13000-15000 people have already graduated from this course, of which 8000-9000 are still practicing.

Textile Centre:
Built 1984 complete with laundry, ironing and tailoring facilities.

Central Heating Facilities:
This facility provides heating to all buildings in the institution using mainly gas. It accommodates as well a workshop for electrical installations. There are also rooms accommodating groups training on matters related to house hold activities, for external employees and civil servants.

The Castle:
One of the oldest buildings in the institution, as construction started as early as 1387. Since then it has been used for different purposes, but today it is used as a residence for 95 children and young adults as well as 27 elder severely and multiple handicapped people, living in 14 residential groups. Additionally the Castle accommodates eight classes of the special school and the library. The Chapel is used for different religious services and celebration.

The Gardener's house:
Once used as a house for the Castle's gardener, it is nowadays used to accommodate 12 youngsters in two residential units.

Gymnasium:

Built 1898, it covers an area of 350 square meters approximately. Activities are performed outdoors for 30 minutes on daily basis. When the weather conditions are not favourable, there are additional three indoor gymnasia for use.

Hospital Wildermuthaus:

Built 1928/1929 as a treatment house for 70 severe and multi-handicapped men and women, and continued to be used as residential accommodation for increasing number of residents till 1988. Since then, residents were transferred to a newly built accommodation, and the building was reused as laboratories and medical examinations facilities. It was also named after Dr. Weldermuth who was the institutions' physician from 1880 - 1889. There are 77 people working in the different branches of this facility (physician, psychiatrics, therapists, speech teachers, etc...).

Therapeutic Pedagogy:

This section of the institute provides therapy treatment on singular or group basis for the adult handicapped, whose severe handicap prevent them from joining different workshops. This building is also used as a meeting place for senior members of the institution.

School:

This building accommodates the school for mentally handicapped children and young people, in addition to offices for the headmaster and school secretariate. There are around 250 students in the school, out of which 20 are non residents. Lessons take place in 38 classrooms and students are taught 61 different types of skills. This building accommodates 60 students, and the rest of classrooms are distributed between the Castle, workshops and the newly purpose built school.

Residential House - Johanniterhaus:
Currently used to accommodate 52 women residents in six different flats.

Workshop:
The main workshop building on site houses different workshops for the handicapped, such as handweaving, painting stamps and work training group. There are also classes for 44 students where they complete their school training. Further workshops are located at other branches of the institution such as Hangweide, Elisabethenberg, Schorndorf and Waiblingen.
Workshops for handicapped offers in total 821 working place for adults (in gardening, textile, etc..) including 184 persons living outside with their relatives. Approximately 100 technical instructor work at the workshops.

Therapy:
In this building there are consulting rooms and working rooms for physicians and specialists for the treatment of patients suffering from Epilepsy and/or mental retardation. This service has been offered for the population since 1883.

Joinery, workshop and vehicle maintenance:
All housed under one roof. There are 30 people employed in eight different sections of building and maintenance. There are also 18 young trainees.

Residential Accommodation:

Residential accommodation on site is arranged in different types of flats:-

A. 20 units of accommodation arranged as terraced houses. Each unit is occupied by 8 handicapped people, and a total of 96 school children and 64 adults (men and women) live in this group of houses.

B. 15 flats arranged in 3 blocks accommodating 90 severely and multiple handicapped children and young people. For ease of identification, balconies of each house are painted in a different colour.

C. Flats for the handicapped, who require intensive care and higher quality of accommodation.

D. Staff accommodation

Horseback Therapy:

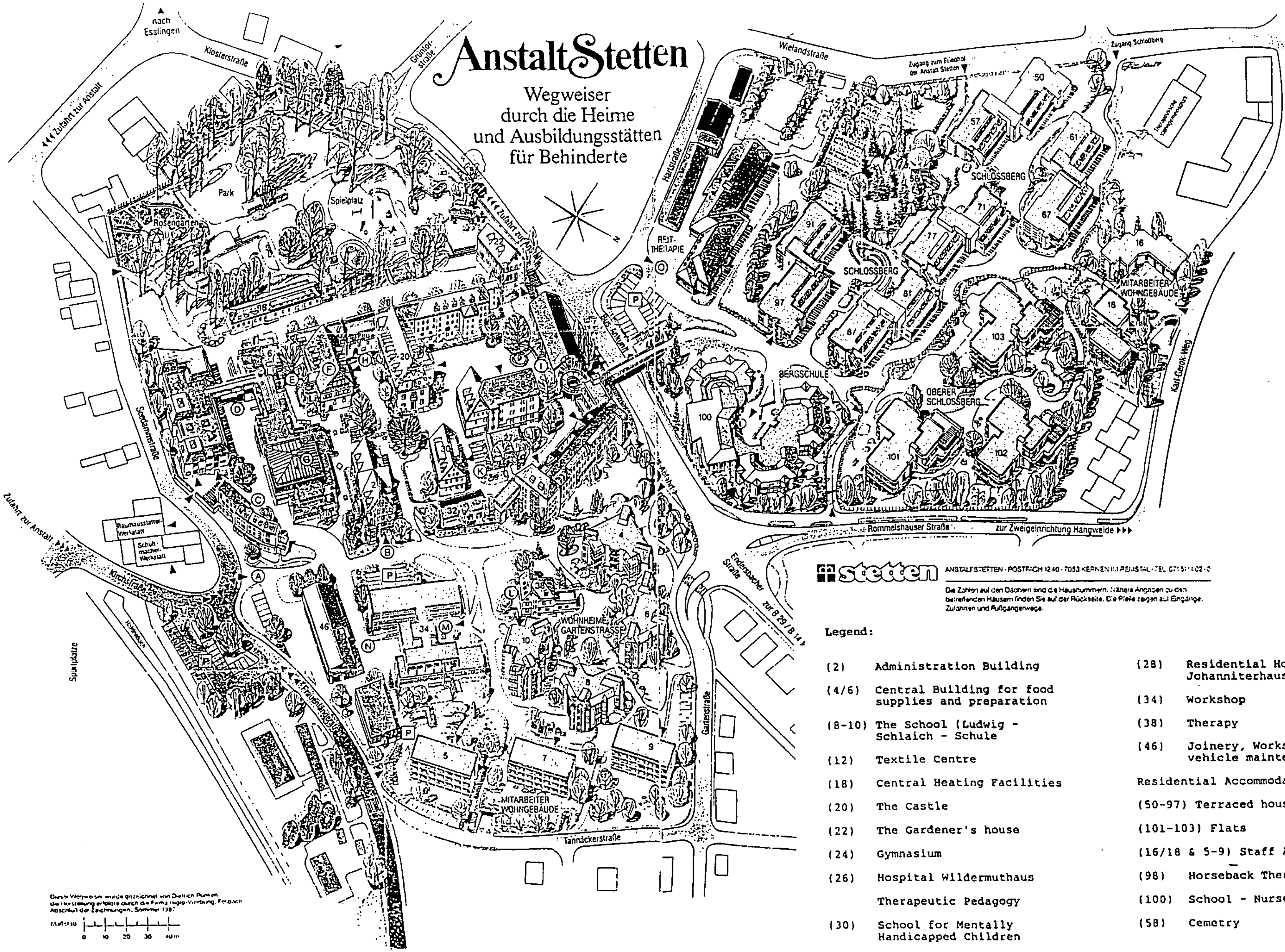
This type of therapy, which nowadays can not be ignored, even for the severely handicapped, is performed in a building which was formerly used for agricultural purposes.

School:

It also contains a special nursery for children. This school provides classes for 90 children and young people, mostly suffering from severe physical and multi-handicap.

Cemetry:

Used for both residents and workers.



Legend:

(2)	Administration Building
(4/6)	Central Building for food supplies and preparation
(8-10)	The School (Ludwig - Schlaich - Schule
(12)	Textile Centre
(18)	Central Heating Facilities
(20)	The Castle
(22)	The Gardener's house
(24)	Gymnasium
(26)	Hospital Wildermuthaus
	Therapeutic Pedagogy
(30)	School for Mentally Handicapped Children
(28)	Residential House - Johanniterhaus
(34)	Workshop
(38)	Therapy
(46)	Joinery, Workshop and vehicle maintenance
Residential Accommodation	
(50-97)	Terraced houses
(101-103)	Flats
(16/18 & 5-9)	Staff Accommodation
(98)	Horseback Therapy
(100)	School - Nursery
(58)	Cemetry

Diagram 7.1 - GENERAL LAYOUT

PART THREE - CHAPTER EIGHT:
School for mentally handicapped children (Lindenhofschule) - Senden

Lindenhofschule in Senden represents the new generation of specially built schools to cater for the needs of the mentally handicapped children in Germany. Careful planning and high standard of finishes can be observed in all aspects of the facility. The project of building this school took six years to be realized. Since its inception in 1981, it met with many difficulties starting immediately after selecting the winning design. In October 1984, however, all discussions over the design were completed and the official building permit was granted. During construction, the project was further delayed by unforseen circumstances such as underground water level, the bad weather conditions of the winter of 1984/85, followed by extremely cold winter during 1985. The official opening of the new school took place on 26th June 1987, (Lebenshilfe, 1987).

The educational aims of this school were defined as to:

1. Help the children to learn about themselves and gain confidence.
2. Care and cater for themselves and their safety.
3. Find their way in life and live life as consciously as possible.
4. Acquaint themselves with social demands and to be part of them.
5. Recognize objects and use them.

The school is designed to provide good facilities for the moderately and severely mentally handicapped children. All the facilities are accessible and connected to each other through a central internal hall "Pausenhof". The Hall, through special arrangements, can also be used for some functions and celebrations. Diagrams 8.1 and 8.2 indicate the general layout arrangement, spreading over two floors and comprising the following facilities, (Lebenshilfe, 1992):

a. Pre-School
b. Main School
c. Day Centre
d. School for severely handicapped
e. Sports facility

Pre-School:

a. Here a handicapped child is prepared by appropriate mental and behavioral guidance to develop to be ready for the school for the mentally handicapped.
b. Children (age 4 +) are taught to work, play and learn with each other. They are shown how to express themselves, verbally even if just to convey requests, to use their bodies in movement and to develop a sense for colour, size and shape. Also to become more independent eg., put on and take off clothes, brush teeth etc.
c. The groups usually consist of 6 -7 children. Close contact is kept with the parents by organizing individuals meetings, parents meetings or home visits. The running of this part of the school is within the overall administration. This section also has two rest and movement/occupational therapy rooms.

Main School:

1. This school is built for mentally handicapped children and young adults who may have considerable developmental delays in motor, perception, speech, social interaction, communication and emotional disturbances. All these influence the learning abilities of children with mental handicap.

2. The school is arranged on two floors:
   a) The ground floor accommodates technical classes (home economics, multipurpose room, school kitchen, etc..) administration and teachers rooms.
   b) The first floor, which can be reached by a staircase or a lift, contains 8 classrooms, each accommodating 6 - 8 students. There are also 4 groups activities rooms and other facilities such as toilets, storages, etc.

3. The school abides by the official German school regulations and teaches subjects like sport, home economics textile work, rythem and craft.
   The school consists of 4 stages:
   a. Lower stage
   b. Middle stage
   c. Upper stage
   d. Workshop stage

4. Every child goes through each stage irrelevant of the kind or severity of his/her handicap. Generally children join a stage according to their ages. The class educational programme is layed down according to the individual social and developmental aspects. Children with especially high teaching needs due to multiple handicaps are considered profound mental handicap. While these children will be grouped together in separate classes, their integration into the other classes of the school remains on of the prime aims of the school.

5. The 'workshop' stage in the school for the mentally handicapped provides the basis for a future job possibility. On completion of this stage mentally handicapped young adults will be given a job at any workshop for the handicapped. Before this transition is completed the school will have been in close contact

with the workshop to monitor the progress and general development of the mentally handicapped young person.

The Day-care Centre:

1. The main school and this centre are in the same complex and therefore used simultaneously by the children. The school follows a more definite programme but the day care centre concerns itself mainly with the emphasis on self help and social co-existence. These aims are practiced in the following:-
    a. Leisure-time activities and hobbies.
    b. Musical
    c. Sport and movement
    d. Health awareness and hygiene
    e. Nutrition and eating habits
    f. Public life
    g. Traffic information
    h. Friendship and partnership
    i. Therapy in speech, physio, occupational

2. This Therapy Centre allows a group of mentally handicapped more time for self-help training by presenting them with a variety of choices and offers to encourage independent choice making. The choices are very much affected by the group wishes and suggestions, but a good balances is kept between training to shop, telephone and public behavior on one hand and relaxation and rest on the other.

3. In addition to its daily functions, this Centre offers many additional uses and activities such as:-
    a. Leisure time during school holidays
    b. Leisure time at weekends.
    c. Walks and cycle tours.
    d. Ice skating
    e. Movement programmes in school hall or room.

f. Crafts with various materials
g. Swimming
h. Group activities: cooking, model-making, model trains, riding and caring for horses, gardening.
i. Playing in open fields.

4. As seen above the day-care centre does not offer all possibilities, but show clearly what activities can be made available for the children. Due to time limit, the main school cannot offer all what a mentally handicapped child needs for learning and training. This can be better achieved by the combined programmes of school, and day-care centre in the one day.

Sports Facilities

Has own entrance and comprises of swimming hall (pool 10m x 4.5mm) with its own changing room area, and sports hall (12 x 18m), also with its own facilities. There are also outdoor sports facilities with different sizes and surface types.

The Educational Programme

1. The pre-school and workshop offer mentally handicapped children and adults who are educable, stimulation and learning. These specialized sections of the school will deal not only with the child's mental handicapped, but also with what influences its thinking, its feelings and its needs. In many cases a child has a multiple handicap, ie., speech and emotional deficiencies which cause it be severely or profoundly handicapped.
2. The main objectives of educational programmes in this school, and indeed in many of such schools, are to enable the mentally handicapped child to head for a more independent life in its family and society. A wholesome and comprehensive programme has to be devised according to the childs potentials, and should be introduced as

early as possible, preferably as an early intervention programme (birth - 3 years). A handicapped child would move through these different stages finishing off with training in a workshop for the handicapped or in some case in outside commercial establishments.

3. A specified individual education plan is layed out for each child according to its needs and deficiencies. In addition to the programmes offered in the main school, (lower, middle, upper and workshops stages), services are also offered in the day-care centre through the following specialists:-
    a. physiotherapist
    b. speech therapist
    c. psychologist
    d. occupational therapist
    e. medical service (Nurse)
    f. social worker

Staff

The specialized members of staff are of various educational backgrounds some are into behaviour modification, others into special education, organizers of groups, child minders and public duty helpers.

Team Work

It is vital to have team work to achieve success. Regular meetings with all members of the team are important to put forward ideas, intentions and contents of a programme and giving reasons for this. Experiences are exchanged and decisions on the extent and volume of programme material given each day trying carefully not to overload the children's capacity. The team has to come to decisions on more formal issues, dates for meetings, letters to parents, substitute staff, school breaks etc.. This can prevent a lot of communication difficulties or unpleasant working atmospheres.

Management

In order to ensure the smooth running of both school and day-care Centre, it was necessary to have an overall management. Due to the separate accommodation of both school and day-care centre, it was decided to have a director for the day-care centre, who is in charge of running the centre, directing the specialized team, helping out where necessary plus supporting her staff to perform to the best of their abilities. She has her room for this purpose.

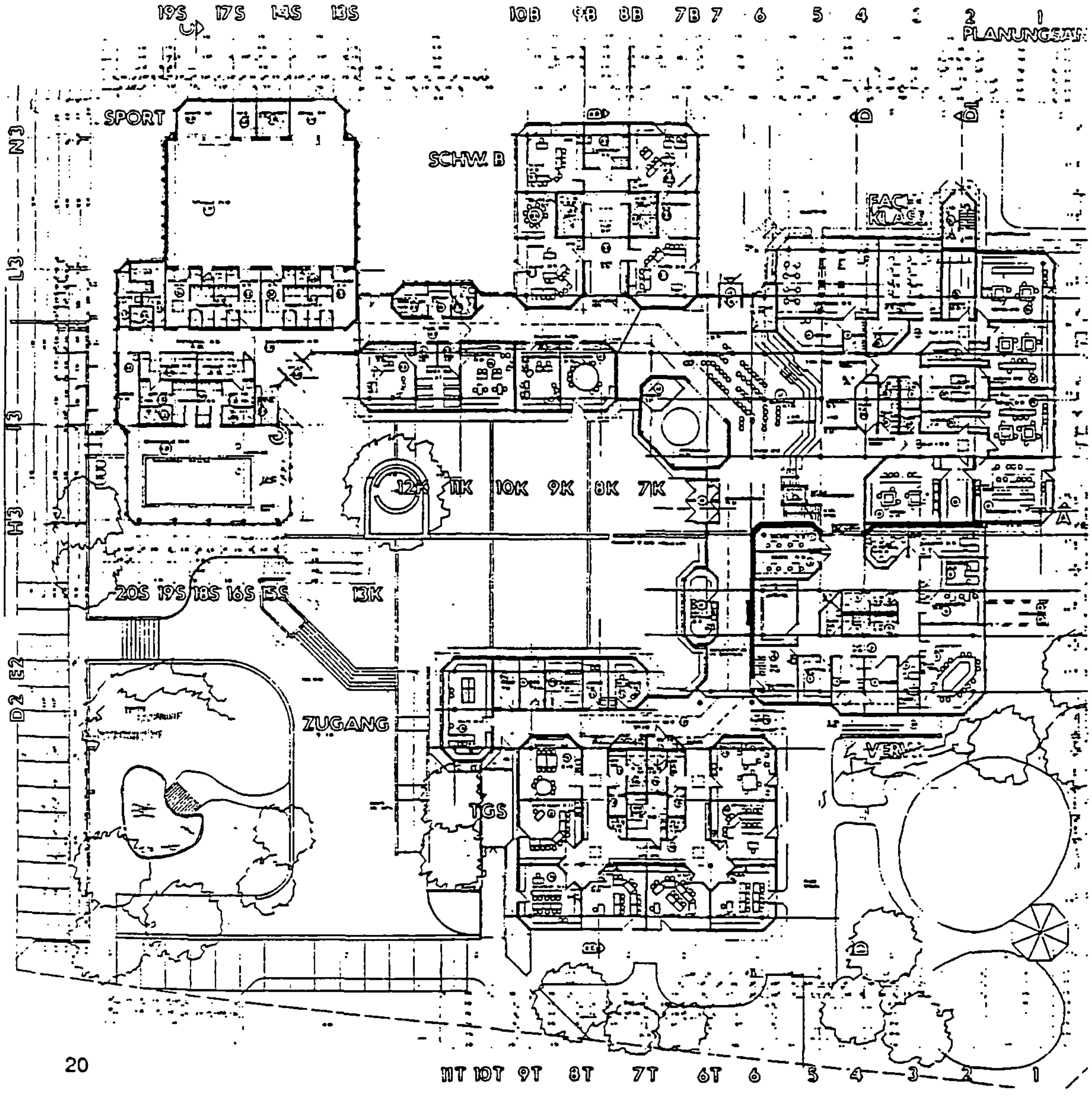


Diagram 8.1 - GROUND FLOOR PLAN

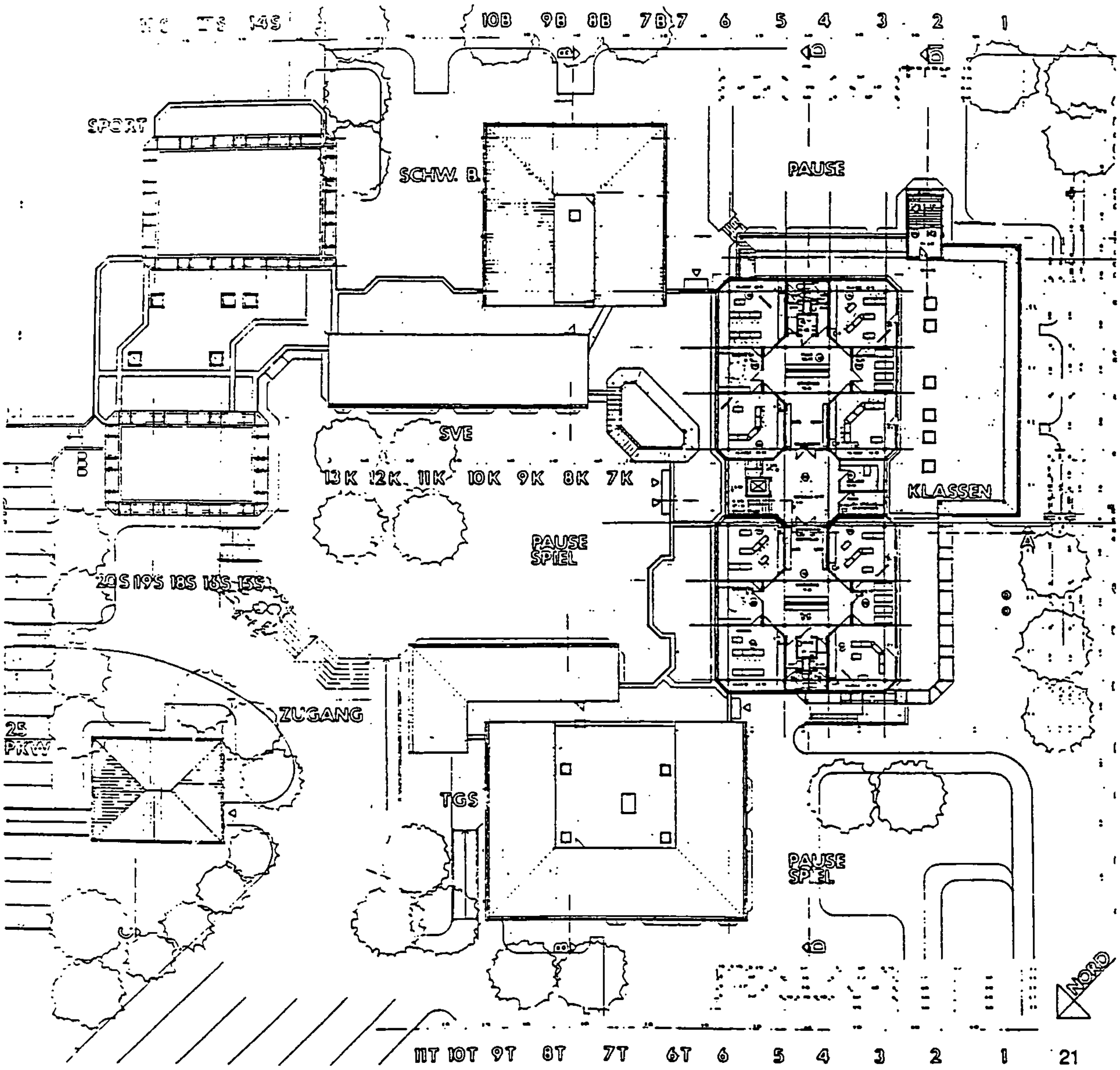


Diagram 8.2 - FIRST FLOOR PLAN

PART FOUR

PART FOUR - CHAPTER NINE:
HELP CENTRE IN JEDDAH, SAUDI ARABIA - A CASE STUDY

INTRODUCTION:

The City of Jeddah is situated on the eastern shore of the Red Sea, (approximately 80 kilometers west of Mecca). While the history of Jeddah goes back to almost 2000 years , its more recent history is closely related to the history of Islam, being the main service centre for Mecca and Medina, two of the holiest cities of Islam.

Following the discovery of oil, Jeddah's role as the main commercial centre of the Kingdom was enhanced and developed to become the biggest city on the Red Sea, and the second largest city in Saudi Arabia, (In 1972 the population estimate was 300,000). Jeddah's population grew from merely 25,000 people in 1938, to an estimated 1.5 million in 1984 (Duncan, 1987).

Modern Jeddah is one of the most attractive and rapidly growing cities in the Arabian sub-continent. It now enjoys a modern road network, an efficient public transport system, and extensive public services. It has also a recently developed sea front promenade (Corniche), which extends for 100 kilometers along the Red Sea, and includes recreational facilities, gardens, artificial lagoons, mosques and many artistic sculptures, (Farsi, 1991).

Other fundamental services, such as medical and educational, improved, almost at the same time and rate as that of the urban development. Services related to the handicapped, however were late to start. In the Western Region for example, the first institute for the blind was established in Makkah in 1962, " Al Noor Institute for Boys", and the first institute to be established in Jeddah in 1972 was "Al Amal Institute for Boys".

The fact is that, although the developments in Jeddah are relatively recent compared with the services in England and Germany, the speed of that development is notable. The first and only institute for the mentally handicapped boys in Jeddah is "Maahad Al Tarbiyah Al Fikriyah", (Institute for Mental Development) which was established in 1976. In the same year a similar institute for girls was also opened in Jeddah. The boys institute accommodates 327 students in 30 classrooms, and is served by 102 teachers, administrators and support staff. The girls' institute provides for 150 girls and is served by 73 teachers, administrators and support staff.

Currently services to the handicapped in Saudi Arabia are being provided by three different ministries:

A. Ministry of Education: is responsible for organizing special education institutes, such as both institutes mentioned above.
B. Ministry of Social Affairs: Services provided by this ministry include the operation of social and technical workshops. The Ministry also provides financial assistance to those children who were not able to join these centres.
C. Ministry of Health: provides services to the handicapped through the various medical centres, where physiotherapy treatment is made available.

With the encouragement and direction of the Governor of Makkah Region, the Handicapped Services Coordination Committee in the Western Province was established in 1988 to overview the different services provided for all handicapped people (physical, mental and psychological). The objectives of this Committee were outlined as follows:-

a. Facilitate comprehensive services for all handicapped people covering aspects such as health, education, social, psychological, etc.., and to help them overcome difficulties which may hinder their progress, education and training.

b. Submit proposals for the development and improvement of services for handicapped people in the Western Region.
c. Taking an active part in public awareness programmes for the prevention of some types of handicap.
d. Hold seminars and lectures to further the cause of handicapped people.
e. Organize permanent and mobile exhibitions for work produced by the handicapped.

The Committee is chaired by the Prince of Makkah Region and has representatives from the Ministries of Health, Education and Social Affairs.

In addition to services to the handicapped provided to mainly the government, there has been some individual attempts to complement such services through charity associations and organizations. The most significant achievement of this type took place in Riyadh, the capital city of the Kingdom of Saudi Arabia, where the Handicapped Children Association (HCA) was established in 1982 and a special Handicapped Childrens' House (HCH) was completed and commissioned on October 1985. This facility accommodates two hundred children with different types of handicap and comprises a medical centre, educational centre, residential houses for sixty children and workshops, (HCH Guide, 1987).

It is generally accepted that estimating the number of children with mental retardation in Arab countries is currently a very difficult task due to many factors, including absence of a unified formal definition of mental retardation, lack of technically adequate assessment tools, and the tendency to hide disability owing to sociocultural reasons (Yousef,1993).

It is suggested that a rate of 3%, which is based solely on theoritical distribution of IQ, is the most widely quoted estimate in calculating number of children with mental handicap in the Arab countries (Yousef, 1993). Accordingly, one can estimate that there are approximately 9,000 children with mental retardation in Jeddah based on 300,000 school age children is 9000 (1).

Educatinal services available to mentally handicapped children are restircted to a very small segment of the population of Jeddah. In 1992, there were 2 governmental institutes for the mentally handicapped children in Jeddah providing services to 477 students (327 boys and 150 girsl) (2). In the meantime private charities and associations were almost non-existing.

Lack of such facilities, combined with a genuine will to help the mentally handicapped led Mr. A. Juffali, a prominent Saudi Arabian businessman, and his family to decide on establishing a special facility for mentally handicapped children in Jeddah. From the outset, the family's intention was to establish a model centre, to be built, staffed and equipped according to the best of modern standards. In order to achieve such an aim members of the family concerned with this project and their consulting team carried out several visits to the UK, Sweden and Switzerland in order to widen their basic knowledge and to come in contact with organizations and establishments in countries known for their high standard in the field of providing services for the mentally handicapped. Descriptions of some of these facilities visited by the writer were included in the previous chapters to indicate the nature of facilities required to provide such services.

In addition, a group of international experts and consultants were invited to Jeddah, during December 1985 in order to assess the situation, and to recommend the most appropriate methods of establishing such a facility.

Preliminary investigations, visits and consultations indicated that the primary factor to be considered in the establishment of such a facility is staffing. A successful and useful service to the mentally handicapped can only be achieved through qualified and well trained teachers and therapists.

Taking into consideration the shortage of the required local staff, two options were considered by the Juffali family to approach the project:

1. To proceed with building a modern facility and provide the majority of staff from abroad.
2. To establish a small centre, where selected highly qualified western personnel are employed to run the facility and train local staff in the meantime. This option assumes that the main centre will be built at a later stage when the number of children and staff reach a certain level.

The Juffali family decided to follow the second option, which represents a more prudent and gradual build up of the project, rather than a hurried instant provision of the major facility. This option will make it possible to train local staff who are more aware of factors which play a major role in the daily life of Saudi people, such as cultural, religious and social factors.

November 1986 witnessed the birth of the "Help Centre" in a small converted building accommodation with three children and three members of staff. The fast progress made by this small nucleus and the great demand for places in this young facility, prompted the family to bring their second phase forward. A preliminary study for the purpose built centre started on 1989 which included the formulation of a brief, schematic design and then the preparation of the necessary engineering documents. It is hoped now that this centre, one of the most advanced facilities for the mentally handicapped in the Region will be ready for occupation by the end of 1994.

A: HELP CENTRE, FIRST PHASE:

The first step towards the fulfillment of this ambitious project took place in November 1986 in a simple facility, (a prefabricated villa) providing a limited service, to three children. This modest start involved three expatriate specialists, headed by Mr. Juffali's daughter, who has a qualification in child psychology.

In 1987 the number of children increased to 10, then to 15 in 1988. By 1990, the centre became well known in the whole region and the number of children who benefited from its services reached 104 (children aged 0-14 years). Over this period, the number of prefabricated villas grew to six and number of staff increased to 34.

At present, this 'day' centre offers the following services and programmes:

a. Early intervention (0-3 years): mother and child are received and enveloped into the love and care of the Centre. The team (a psychologist, speech therapist, physio-therapist, nurse, social worker and specialist in behaviour modification) will help the mother cope with, stimulate and encourage her baby to exercise and learn what is shown to her. Questions are answered, moments of despair are dealt with, and thirst for information is quenched. The programme also demands regular attendance to the Centre (twice a week for two hours). Home visits are made by the staff once a week during the baby's first year of life. This programme will give the baby a basis to help it move on to the next stage.

b. Pre-School (3-6 years): This a small group (about six-eight children) who attend the Centre daily from nine - twelve, five days a week. The head teacher and her two assistants further their abilities and emphasise self help and oral expression. Pre-reading and pre-writing skills are taught at this stage.

c. The Morning Programme (ages 6-10): This programme holds the largest number of the Centre's children who attend five days a week like a regular school and who are taught to read and write in addition to the basics in speech, song, sport, self-help, art and craft, religion and household duties. They are grouped into two groups of 10 - 12 children in four different rooms.

d. Pre-Workshop (ages 10-16): According to Saudi educational law, boys and girls above the age of 10 years are forbidden to be grouped together in schools, theatres, outings or sports functions. Separation is therefore mandatory, much to the displeasure of the staff, especially the western members, as this too means total separation of male and female staff. Not only does this mean extra costs (double equipment, accommodation, teaching aids etc.) but also an added complication: female staff teach the girls and male staff teach the boys.

e. In addition there are several individual sessions where a child receives a one-on-one session with the physio-therapist or speech therapist in the afternoons. This applies to the children who are enrolled in any of the morning programmes but need extra sessions.

The Centre deals with children's behavioural problems, delayed development, learning disabilities, speech and hearing problems, physical handicap combined with mental handicap. The Centre specifies clearly that it is a centre for mentally handicapped children first and it therefore, does not accept children with physical handicap only. There are other centres in Jeddah which care for the physically handicapped, but they are based on physical and mental care, lacking the trained staff to stimulate and teach the children basic skills of self-help which are of paramount importance to achieving gradual independence.

The Centre also cares and helps mothers of babies with medically confirmed mental handicap and it offers guidance and support to the parents in all aspects dealing with their child. It also provides advice on what special equipment is necessary for their physically handicapped child, where to buy it and how to use it. The same applies to children with hearing impairment as there is an audiologist who will test the hearing and recommend a treatment.

All the Centre's children enjoy full medical and dental care through agreements made with two hospitals in Jeddah whereby a discount is given to the child on any treatment offered. The charity cases are given letters from the Centre to present to the hospital to indicate that the Centre will carry the costs of their treatment. The Centre also supports the very needy families by providing them with essentials for their child: Clothes, useful toys, equipment and food.

The six prefabricated villas, comprising the present accommodation of the centre are located in a quiet residential area, within a housing camp occupied by senior employees of Juffali Corporation. The children therefore, have the benefit of using the excellent sports facilities provided for the residents. These include a large swimming pool and two tennis courts. This use, however, was limited to mornings usually to minimise any disturbance to residents. A swimming gala is held once a year at the pool, and a sports day takes place once a year on the tennis court.

The present accommodation has been the focus of admiration by many a visitor. Classrooms are appropriately furnished and the space provided is adequate. The speech department has had an audiology laboratory added and can now perform hearing tests. This has been an important addition to the Centre as many of the children are developmentally delayed, due to impaired hearing as well as mental handicap.

The Centre displays extreme enthusiasm shown by all members of staff and a happy atmosphere in all departments, which in turn is reflected on the children. The main contributor to this is the positive attitude and approach by the management of the Centre, which is underlined by the "Philosophy of Help Centre, 1989":

> We at the Help Centre firmly believe that every child is a unique creation of God and as such is entitled to have his physical, mental, spiritual and cultural needs met.
>
> We believe that the family is the basic unit of society and its integrity should be maintained at all times. It is through family support and parent counselling that we help them cope with the handicapped within the family.
>
> It is through the dedication of each member of the Help Centre team that all children are provided with an individualized treatment plan which prepares them towards independence in as much as their physical and mental abilities allow them.
>
> We believe that the parents should be involved in the planning of the individualized treatment plan and should be an integral part of the Centre.
>
> The members of the Help Centre work as members of a multi-discipline team and co-operate with other professionals in the medical and educational field in order to provide the ultimate care for each child enrolled in the Centre.

> It is not enough to provide facilities and staff for children with both physical and mental disabilities but that we try and educate them in order that they may assume their rightful place in society.

PROCEDURE FOR ADMISSION TO THE CENTRE:

As indicated earlier, the Centre became a very sought after place, only two years after its initiation and increasingly, more and more people are finding their way to its doors, asking for help and admission for their children. Therefore, it became necessary to establish strict rules and procedures for admission, which are compatible with the nature of the Centre and its objectives.

ADMISSION:

When application is made, an appointment is set for an initial interview. The child and its parents are interviewed by a member of the Social Services Department. Necessary documents (medical report diagnosing a mental handicap, a vaccination certificate, a birth certificate, identification cards or passports) are requested to enable the social worker to fill in the forms fully. The file is then handed over to the psychology department, which then arranges to see the child and assess it. These findings determine whether the Centre can accept the child in any of its programmes.

According to whether a vacancy is available the child is either enrolled or put on the waiting list. Priority is given to Saudis and non arabic speakers are not accepted. The Social Services Department determines whether or not the child is to pay any fees. The fees are payed on a half-yearly basis and a deposit is payed at the end of each year to encourage parents to commit themselves to the next scholastic year. From here on the child is officially enrolled and will stay in the Centre moving from one programme to the other according to its abilities and progress. A child is only then discharged if the parents request it, or if the parents have been extremely uncooperative and repeatedly headed no warnings or failed to recognise probation periods.

Interaction with the public is one of the most sensitive areas the Centre is dealing with. Against a conservative social attitude and lack of public awareness, two departments of the Centre which have a significant role to play with the parents are:-

A. The Social Services Department
B. The Early Intervention Department

The following is a general description of the functions and operations of these two departments.

THE SOCIAL SERVICES DEPARTMENT:

The Social Services Department plays a significant role in initialling and completing the admission procedure by conducting the "initial interview", and determining the financial status of a child's family. It also acts as a means of communication between the Centre and the families. The "initial interview" is not just a matter of filling in forms about the child's background and development, it is the basis to a relationship which both family and Centre can build a lot on. This interview gives the social worker an impression as to how the child is handled by both parents, how it reacts to them, how the parents react to each other. These impressions are later discussed with the psychologists who will assess the child. Very often, this initial interview is the one and only time the Centre gets to see the father, as it is common in Saudi Arabia to leave schooling matters to the wife. Also, during the interview which lasts between half an hour and one hour unexpected issues surface which can be of vital importance to assessing a child. It might show up a certain problem (psychological or emotional) in either the mother or the father or even a disharmony between father and mother. Parents might hesitate at giving out private information but soon realise that is dealt with confidentially.

Parents are contacted when their child has been assessed and accepted and the father is asked to fill in a confidential form stating his income and expenditure. This is studied by the social worker and upon it the Centre determines whether the child is to pay full fees or just a percentage, or no fees at all. In the case of a non-paying child (a charity case) the Centre settles all dental and medical bills and provides the child with any necessary equipment to enable is to progress. The social department receives and deals with the parents' needs and requests and organises the appointments at the different hospitals and clinics with the help of the Centre's nursing department.

The outcome of decisions reached during staff meetings is handled by the Social Services Department as it is the only part of the Centre which enjoys a close and confidential relationship with the child's family. The same applies vice versa and it is vital to report to the concerned department in the Centre whenever demands or requests are made by parents.

The social worker and another member of staff would pay the family a visit as soon as possible after the child has been accepted. A suitable appointment is made and it is emphasised to have the father present. The purpose of this visit is to see the members of the family in their home environment and measure up the condition of the area, the house, the furniture (this is helpful to determine the fees) and also to observe the child in its own home among its family. Another visit might be planned for a later date or when the need arises.

The Social Services Department is the only part of the Centre which has detailed data on each child and its family. It is up to the department's discretion to give out the necessary information to the right person. At a later stage this information will be fed into the Centre's computer to compile a general survey which will be used in the accumulation of data related to mental handicap on the regional and national level.

EARLY INTERVENTION DEPARTMENT:

The past two decades witnessed an upsurge of interest in early childhood programmes aimed at children exhibiting developmental delay. Monitored programmes at Macquarie University, New South Wales, Australia in 1977, showed that children who took part of a specially structured programme with Down's Syndrome children, have shown significant improvement on measures of gross and fine motor, language and personal-social skills. Such results were recorded only 12 months after the commencement of this special programme, (Ward et al., 1987).

This fact was realised in the Centre soon after it started, and an early intervention programme team was formed compromising a social worker, a psychologist, a physiotherapist a nurse and a speech therapist. The function of this programme was defined as follows:-

- to assist the parents to cope with the trauma of having a child which is developmentally delayed.
- to facilitate the acceptance of the child by parents and siblings as a full member of the family.

- to prevent the subsequent development of secondary disabilities (physical/emotional).
- to offset the inevitable delay in the development of these children by systematic teaching and training programmes and by guiding the parents in how best to nurture the child's progress.

In the process of establishing the Centre the management met with mixed fortunes of frustration and hardships, but it had also its share of rewards. As a pilot project of this kind, the Centre had to deal with many considerations related to social and cultural factors. Two of the most significant aspects are the parents' attitude towards the mentally handicapped and public awareness.

SOCIAL HABITS AND PARENTS' ATTITUDE:

As a charitable organization, the Centre ardently believes in and indeed exercises equal rights and opportunities to everyone. Personal relations and connections however, play a major role in everyday life and business matters in the Arab world. This attitude creates many difficulties to the management of the Centre as many applicants believe they can admit their children in the centre by using influential or business connections. However, as mentioned previously the the Centre became a very sought after place and the waiting lists increase in length day by day. It is therefore important to explain the situation to the parents of applicants and ask for their understanding as well as explain clearly why they have to be patient and wait for their turn to be interviewed.

The Centre's management staff believe that in Saudi Arabia, like all other countries, parents of handicapped children often need as much help as their child. The Centre has intensified its activities in this field through the social work department, which takes on the task of aiding and providing for the needs of the family as a whole. The social services provided by the Centre extend into the child's home, but the effectiveness of this service has been reduced in many cases by the conservative attitude of families and their reluctance to allow outside intrusion on their privacy, and hence cause their family's "misfortune" to become public.

In some cases this negative attitude results from a genuine concern not to allow the family's "misfortune" to become public for fear of ridicule or damage to their reputation. This is especially noticeable with the more educated parents, who sometimes cannot cope with the idea of having a mentally handicapped child of their own. One the one hand, they want to give the impression that they know what is wrong with their child and demonstrate that they have tried their best to help it, but on the other hand they cannot hide their hesitance, reluctance and confusion. The less educated, or uneducated parents are less argumentative and usually believe firmly in the wonders of medicine. Although the Centre is not a medical Centre, they like to believe that their child will somehow be healed or at least improve. Some firmly believe that their child will improve and no longer be mentally handicapped. Others will take their handicapped child to an 'arab medicine' man who will have put the child through some undoubtedly agonizing experience in the hope of ridding the child of this ailment. It is not quite clear as to what methods are used but it has yet to prove its effectiveness.

Religion also plays a very strong part in Saudi daily life. Saudi Arabia is the birth place of Islam and strongly complies with Islamic Law. Traditionally, the Saudi Arabian society is considered to be quite conservative compared to other arab and moslem societies. The application of religious rules are strict and radical, especially with matters related to womens behaviour, conduct, rights and obligations. As a result, women have a very confined role to play, and with few exceptions, they are not allowed to mix with "strange" men, and can only travel in the company of a husband or brother, wearing a block veil in public. Females are segregated from males throughout their education and practical life. However, Saudis are now gradually accepting the changes brought on by western technology, as well as the semi-permanent western community in their midst. This transformation has advanced furthest in Jeddah, a trading post that remained open to the outside world for centuries.

As a result of women's restricted role in life outside home, in some cases the Centre has to deal with fathers alone, and rely on their cooperation, be it the decision to apply to the centre, to pay the fees, to drive the child to and from the Centre (women are forbidden to drive in Saudi Arabia), or merely accepting assistance and guidance from the Centre.

In most of the developing countries, the west is looked upon as an ultimate authority on medicine where cures are found for all ailments. Many parents of mentally handicapped children are hopeful that this source would also cure their children. While some families are bitterly disappointed when informed that their child's ailment is incurable, they then resign to their religious beliefs and find comfort in saying, "It is God's will". This attitude, however, when it becomes resigned and negative, can be detrimental to the child's chances of improvement.

PUBLIC AWARENESS:

Information released through the media to the public, by government or private Centres, is extremely limited and scarce. The high percentage of illiteracy, especially amongst the nomadic Bedouin population and social inhibitions in the urban population, prevented this matter taking its rightful amount of advertisement or public awareness efforts. Parents hear about the Centre from relatives, friends or the medical sector. It is common to get written referrals or telephone calls from medical establishments referring a client to the Centre. It is also common to find a relative, friend or neighbor call on behalf of a family because the concerned parents are too embarrassed to contact the Centre directly. Inspite of the obvious lack of public advertisements, the flow of clients is endless and it is one of the social department's most difficult tasks to turn applicants down for one reason or the other as the first and foremost purpose of having a social services department is to aid and support people.

The Centre has been active in establishing good public relations within the community, keeping in mind that the ultimate objective is to increase public awareness about the mental handicap. Some of the activities in this field are:

a. Printing a quarterly newsletter.
b. Printing a calendar with drawings painted by the Centre's children.
c. Performing an annual play where all children take part.
d. Establishing contacts and arranging visits to special public service centres such as the Jeddah International Airport, and the Jeddah Port.
e. Contacts were also made with some factories in Jeddah in view of creating future employment opportunities for the Centre's children.
f. Visits to the Centre were arranged for journalists and newspapers correspondents, resulting in the publishing of positive articles about the mentally handicapped children and their treatment.

Contact have been also made with various Jeddah schools (Arabic and foreign) and visits by the students of these schools have been arranged to introduce to them the idea of handicapped children and the care provided for them. The Centre's children have been to visit some of these schools to attend certain functions. An exchange of correspondence has taken place and the awareness on both sides has defenitely embarked on a good journey.

B: HELP CENTRE, SECOND PHASE:

Phase Two of the Help Centre Project started almost immediately after the opening of Phase One in 1986. From the outset, the Juffali Family were convinced that the establishment of a highly well designed and equipped centre is important for the following reasons:

- The Centre will provide better facilities for the children, and more efficient place and environment for the users.
- The new facility would attract the attention of the public to the existence of such children, and the need to provide for them.

The development of the new centre went through three main steps:-

a. Study and research
b. Site Selection
c. Design development

During 1989, positive steps were taken towards the realization of the project. Terms of reference for the development and design of this Centre were formulated. The objectives of establishing this centre for mentally handicapped children in Jeddah were stated as are to provide the following:

a. A purpose built centre, where mentally handicapped children receive special education and training leading to the improvement of their personal development and social integration.
b. A better chance for mentally handicapped children to lead a full, enjoyable and active life through specially planned educational programme.

c. An expert guidance to the families on methods of improving their children's physical and mental abilities, (Help Centre, 1989).

A brief was prepared, outlining special considerations to be accounted for during the project development stages, such as:

- The Centre should meet all physical and educational needs of the children and should provide for a friendly and homely atmosphere.
- The design of the Centre should be flexible i.e. individual spaces can be used for different purposes by manipulating their physical layout and furniture arrangements.
- Special consideration should be given to indoor and outdoor play areas in order to create an amusing and stimulating environment for the children (suspended toys and mobiles).
- All areas used by children should be made accessible for various groups of handicapped children.
- Physical safety of the children is prime criteria in designing indoor and outdoor spaces. Equipment, tables and fittings should have protected edges, and all surfaces must be finished in soft material.

The search for an appropriate site for the project started as early as May 1988. The main criteria for site selection were set out as follows:-

a. The recommended total area of land to accommodate all components of the project is 20,000 m2 or more, but not less than 18,000 m2.

b. The site should be located in a district of Jeddah served by public utilities (water, electricity), public services such as shopping, public transport and near to an established medical centre (Hospital). Connection to the main city sewage network would be advantageous.

c. The site must be located at a quite and reasonably low density built up residential area.

By 1990, a prime site in Jeddah, with total area of the 43,000 m2 was acquired by the family Juffali. This site was selected amongst 18 other locations around the city, is conveniently located and have easy access to different social, commercial and medical services. It is connected to the main city sewers, water and electricity, and can be easily reached either by private cars or by public transport. The total site are is adequate to accommodate this project and any other future expansion.

During the early stages of the project, there was a tendency towards providing some residential accommodation for the handicapped children. This idea, however, was discarded at a later stage for the following reasons:-

a. The mentally handicapped children should be treated exactly like normal children in terms of their daily schedule, i.e. they should live at home, and go to school during the day.
b. It was felt that living in the Centre could deprive the children from a very important aspect of their development i.e. Love and care of the parents.
c. Parents participation in training and educating their mentally handicapped children is considered as an essential part of the educational process of these children. Parents should not be relieved from playing this important and essential part of their children's physical and emotional development.

One of the most important tasks to be completed at the early stages was to establish a schedule of accommodation. This schedule would include provision of space for all activities within the Centre, accommodated in a main building, administration section, educational classes (satellites) staff residence and other facilities (Appendix 5).

Six architectural offices were invited to present schematic design ideas based on the detailed brief described above. The winning design was based on the concept of a central facility (administration and activities) serving educational facilities accommodated in five satellites, divided according to age groups.

Due to the special needs of mentally handicapped children, extra care was given to the arrangement of classrooms and their internal layouts. Classrooms had to provide spaces for education, rest and other activities such as simple food preparation. Direct and easy access to toilet facilities had to be provided in addition to individual treatment rooms adjacent to the main classroom area.

When completed, the facility will provide a comprehensive, well planned and equipped centre for the mentally handicapped children in Jeddah (See Diagrams 9.1, 9.2, 9.3 and 9.4). The central and highly visible location it occupies will certainly intensify both public and private awareness of the mentally handicapped needs. It is hoped also that the building of such facility will encourage other wealthy families to provide similar facilities in Jeddah and other cities of the Kingdom.

Phase Two of this project caters for children up to 16 years old only. The Juffali family realises that further work needs to be done in order to provide suitable services to the mentally handicapped, who are above this age. Phase Three is being considered now where programmes for training and working in sheltered workshops should become available, at levels compatible with the varying degree of the mentally handicapped's capability. Part of the programme for this phase will be implemented on the same site as Phase Two, and other more specialised facilities will be located nearer to some of the family's industrial concerns.

The prospects of positive reaction towards the promotion of this cause are high. At the end of 1992, it was announced that special facility for the handicapped in Jeddah, similar to the one exists already in Riyadh will be built in the near future, and a private centre for speech and hearing (Jeddah Institute for Speech and Hearing) is planned to start operating early on 1993. In the meantime public interest in Help Centre is increasing and more parents of mentally handicapped children are visiting the centre and applying for their children's admission. At the end of the academic year 1993, the waiting list exceeded 100 applicants and the lack of space in the current temporary premises is the only reason why only 30 applicants will be accepted. No wonder that the most frequent question is being asked now by those concerned with mentally handicapped people in Jeddah is, "When will the new facility be ready?".

Notes:

(1) Statistical Guide - Jeddah. Jeddah Chamber of Commerce, 1991.

(2) Directorate General for Special Education, Ministry of Education, Kingdom of Saudi Arabia. Annual Report, 1992.

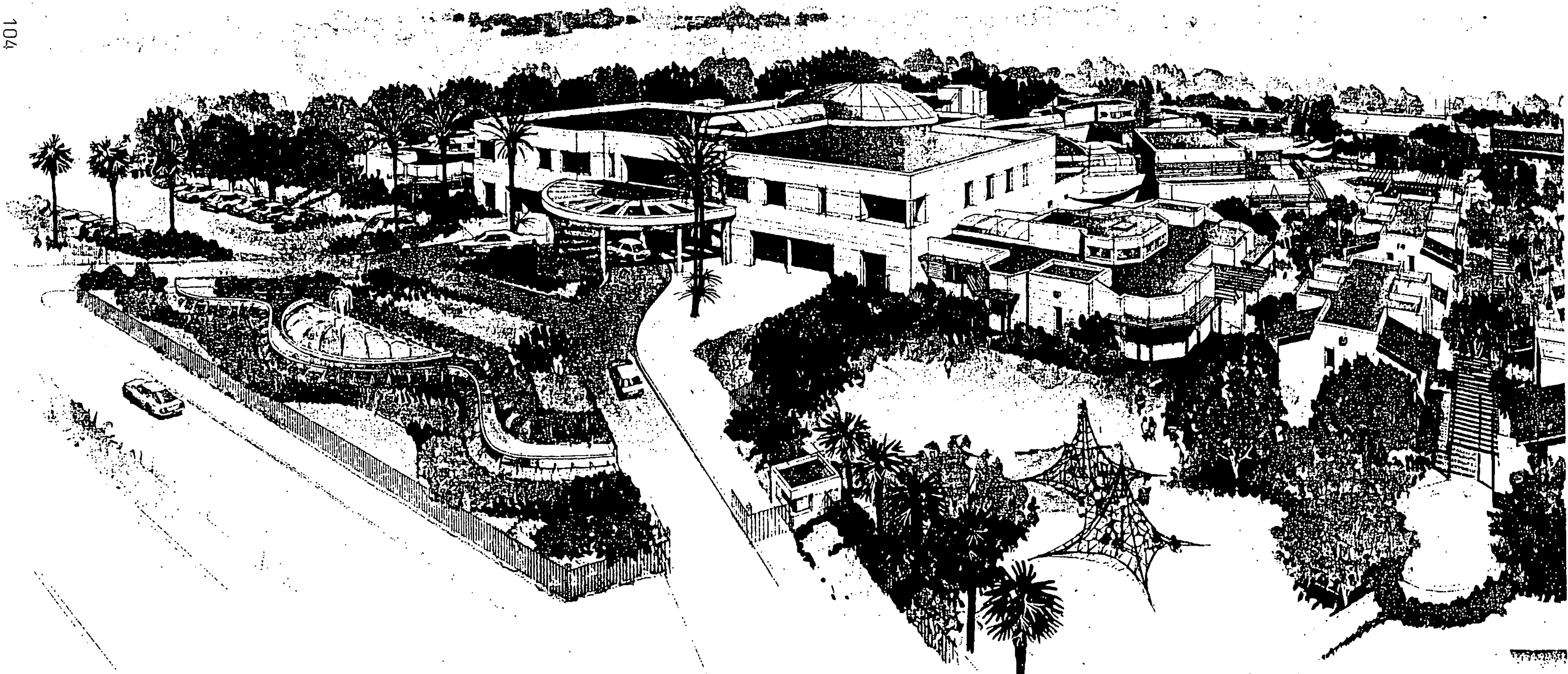


Diagram 9.1 - GENERAL VIEW

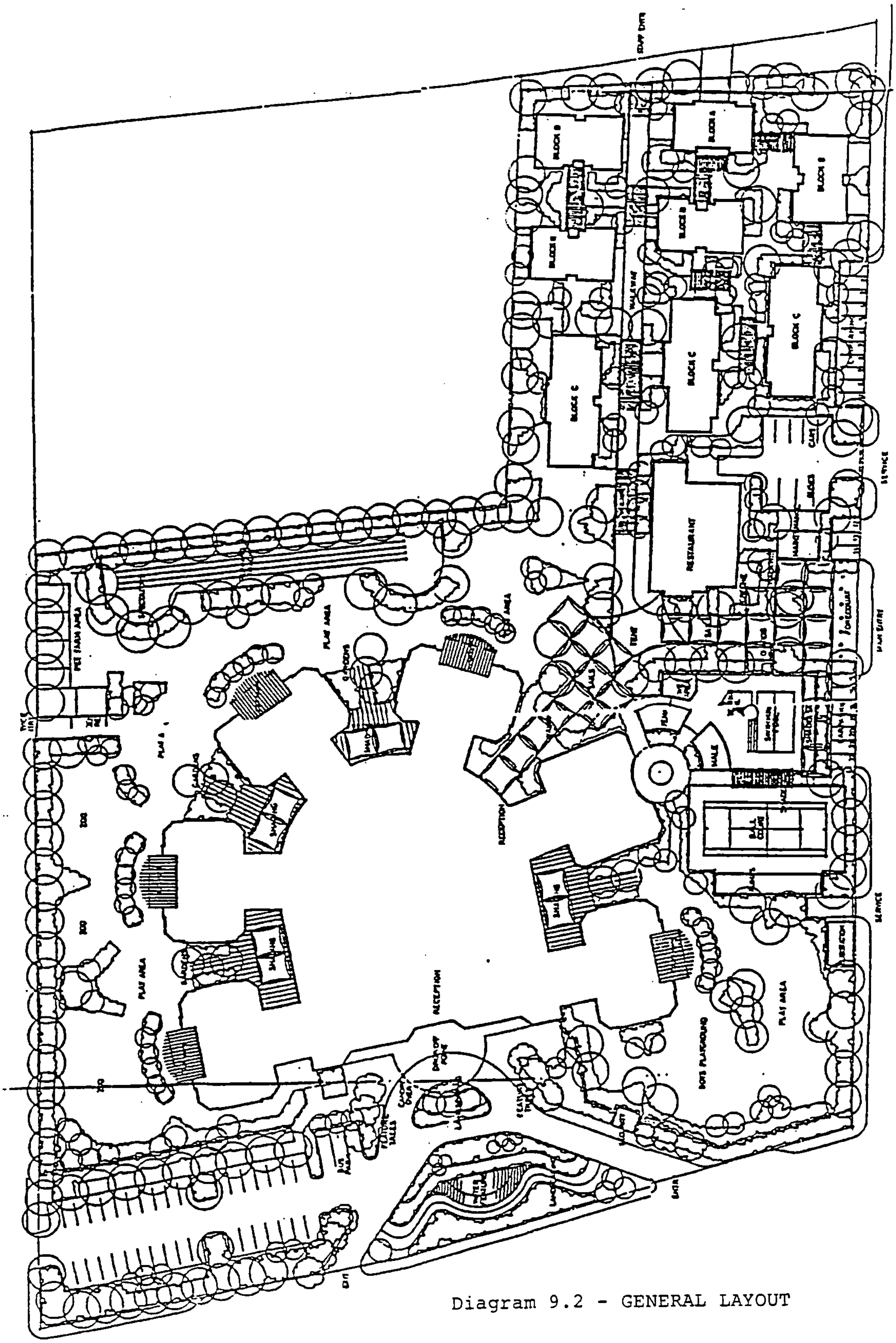


Diagram 9.2 - GENERAL LAYOUT

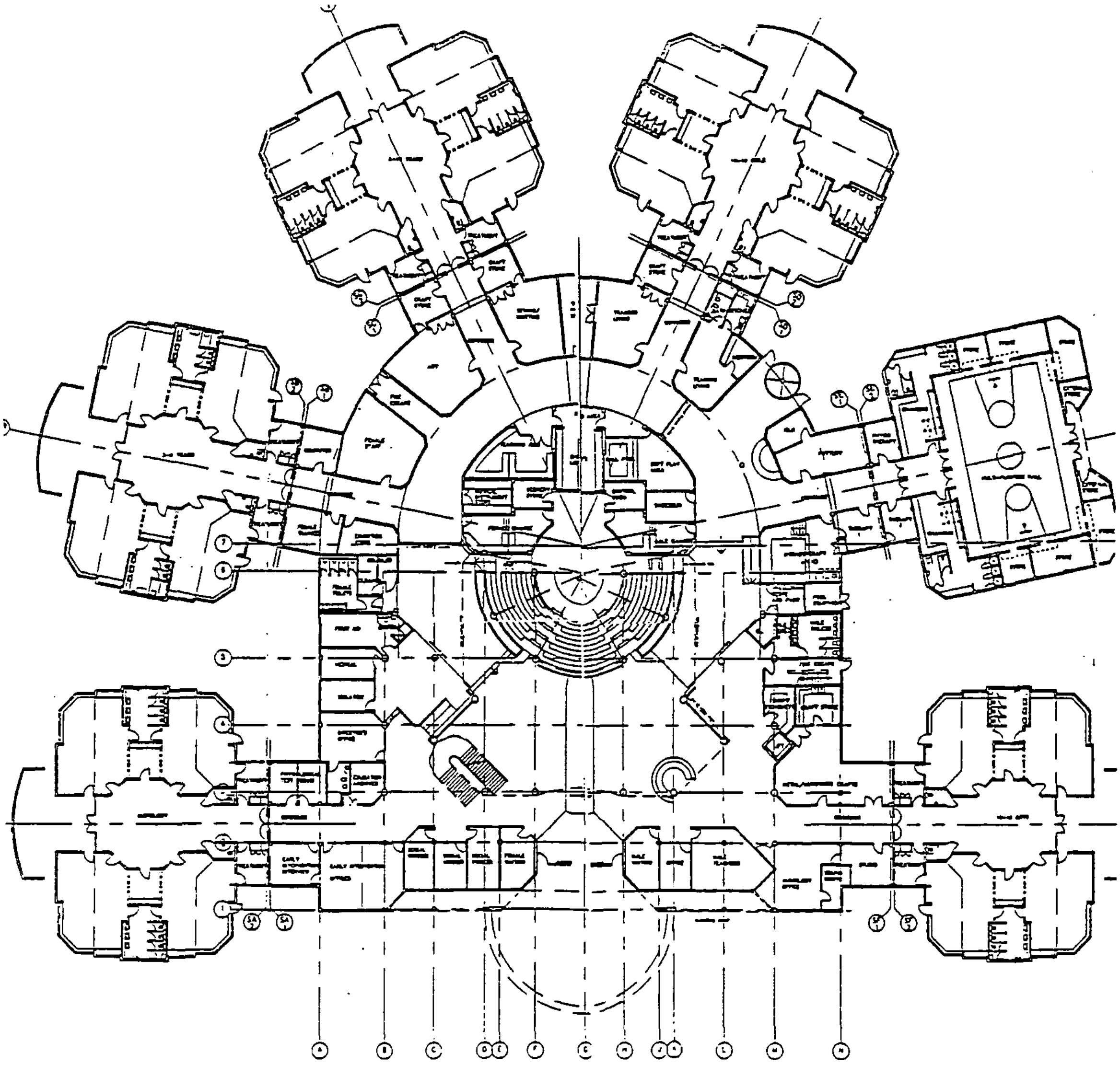


Diagram 9.3 - GROUND FLOOR PLAN

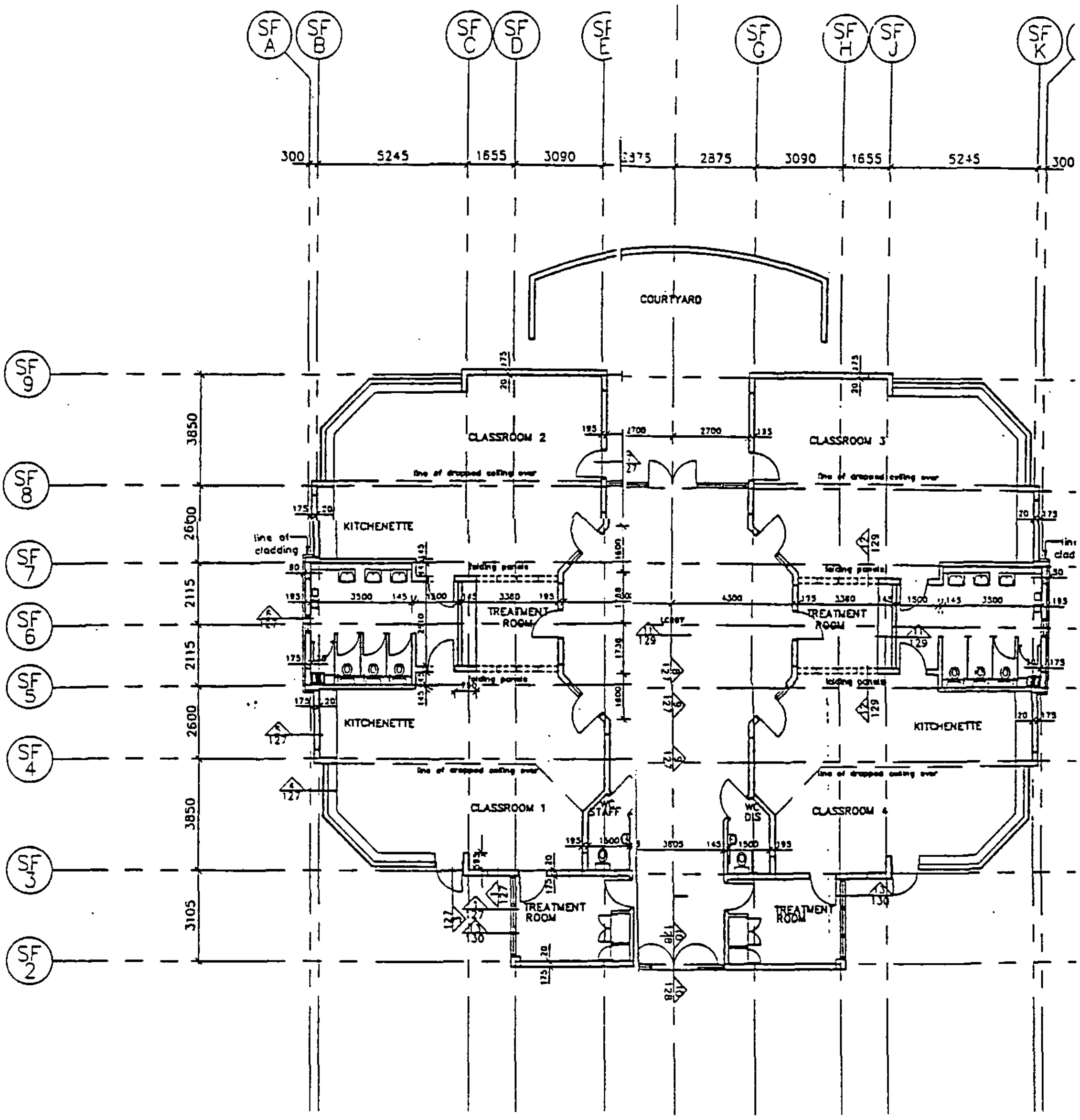


Diagram 9.4 - SATTELITE LAYOUT

PART FIVE

PART FIVE - CHAPTER TEN:
CONCLUSIONS AND RECOMMENDATIONS:

The main objective of this work, as stated in the Introduction (Chapter One), is to highlight the main aspects of mental handicap, and describe progress made in different locations and societies towards improving care for people with mental handicap. This Chapter summarizes the main conclusions and recommendations related to different aspects of services to the mentally handicapped such as education, training, community services (medical, housing, welfare, etc.), family help and public awareness.

Conclusions:

1. The mentally handicapped child, whether living in a developed or developing society, is first of all a child with the same needs as any other child, and also with the same rights to have those needs met. By definition, if people are handicapped they have special needs and should be given special consideration and special facilities to enable them to compensate for their handicap. The mentally handicapped are members of the society, which is obliged to provide the special training and education and social support which they need.

2. There is a strong need to change the image of the handicapped as "different and frightening". A less isolated existence for them requires knowledge and understanding on the part of all of us. Mittler (1979) suggests that the way in which a society goes about identifying its handicapped members tells us more about the society than about the handicapped. He concludes that the values that a society sets on the importance of helping its handicapped members, the kind of services it provides and the resources that it is prepared to allocate reflects its standards and priorities.

3. In many cases, it has been proven that mentally handicapped people are capable of learning to a far greater extent than was previously thought possible, provided that they are given skilled help and time to learn. Education and training for the mentally handicapped is a continuous process, which begins as early as birth.

4. Working with handicapped children is always difficult because it involves such a complexity of individual needs in the children and their families. Hence it requires considerable expertise in the multi-disciplinary team.

5. A great deal of progress has been made during the second half of this century towards providing the necessary services to the mentally handicapped, and it is hoped that in the future such progress will be maintained.

Recommendations:

1. The costs to society, to the family and to the handicapped child are so great in terms of suffering and expenditure that most nations have developed programmes addressing different problems of the handicapped. A major factor requiring increased attention is early identification of handicaps in order to prevent their continued progress and to intervene with corrective actions. Parents should be encouraged to take part in the early identification process, and get all help they require from government and voluntary organizations. While the system of early detection currently applied in Germany is voluntary and not legally binding, it produced good results in early identification of mental handicap amongst children.

2. Parents should be made aware of their child's mental handicap as early as possible, and be informed of the many problems which may occur particularly during the early months of life.

They also need as much information as possible, and as early as possible in order to help them to deal with their own child. Parents of the mentally handicapped child must be involved with the child's daily life and development from the very beginning. The Warnock Report (1978) stressed the need for early intervention, and suggested methods of communication between service agencies and the parents of children with special needs.

3. Parents need to be helped to play a much more central part helping the learning and development of their handicapped children. This involvement should begin as soon as the handicap is identified, and should be developed when the child reaches schooling stage. Parents and teachers should work in full partnership to help the child's development and meet his/her needs at all stages of his/her life. Special training programmes, such as the Portage System (1), can enhance parents's involvement in their child's development.

4. Possible alternative for providing mentally handicapped children with education are ordinary schools, special schools, special classes, nursery schools, play groups, day nurseries or any combination of these. In some cases, it may be preferable for the child to remain at home and for the parents to recieve help from a visiting teacher or other specialist (Mittler, 1978).

5. Funds allocated by government and statutory authorities, do not come close to meeting everyday costs of institutions for the mentally handicapped. This is the case not only in developing countries but in many developed countries as well, such as the UK. In the absence of adequate funds from such authorities, voluntary income becomes of substantial importance. Hence public awareness programmes play a vital role to promote the cause for voluntary support for such institutes, as successfully demonstrated in Germany by "Lebenshilfe" and

"Action Problem Child" programme.

6. Government and private concerns should not spare efforts to promote the public awareness to the problem or integrating handicapped children into society. Public information programmes using all available mass media, should be developed and disseminated on a large scale in order to help the public understand problems of handicapped persons living under special conditions. Small community development programmes should be established, especially in rural areas, geared to alleviate the isolation of handicapped persons and facilitate their full participation in as many aspects of life as possible. Activities in this field of voluntary groups, such as MENCAP and CMH should be encouraged publicly and privately.

7. While it is established government policy in the UK to eliminate large social, medical and educational institutions for the mentally handicapped, this trend should be encouraged and applied worldwide. Such institutions should be replaced by smaller units which provides a more homely environment and a better standard of residential care e.g. (Camphill Houses). There is a need for a range of residential accommodation for mentally handicapped children and adults, including hostels, group homes and varying types of supported accommodation (Stetten in Germany).

8. As indicated in the Help Centre experience in Jeddah, finding the specially qualified personnel was a main obstacle against establishing a full fledged facilities for the mentally handicapped. This situation is prevalent in most developing countries and in some developed socisities as well. In order to overcome this shortage, special courses at universities and colleges of education should be provided for teachers wishing to specialize in the education of children with special needs.

These courses should aim at:-

(i) developing the teachers' awareness to recognize the special needs of the child.

(ii) emphasizing the teacher's role in the assessment of child's educational needs.

(iii) giving knowledge of the range of various forms of help to the mentally handicapped given through special educational provision and the role of specialist advisory services.

(iv) providing the teacher with an insight into the role of the parents as partners in the education of their child.

Notes:

(1) The Portage System was first funded in 1969 by the American Bureau of Education for the handicapped, and was originally designed for use with parents of pre-school mentally handicapped children in the rural area of Wisconsin, taking its name from the town of Portage. This system makes use of "home advisor" who visists families once per week, setting goals and preparing training programmes for children who are develop mentally delayed. A revised edition of the system was produced in 1976.

APPENDICES

APPENDIX 1:

RESOLUTION APDOPTED BY THE GENERAL ASSEMBLY
/on the report of the Third Committee (A/36/37)/
International Year of Disabled Persons

The General Assembly,

Recalling its resolution 31/123 of 16 December 1976, by which it proclaimed the year 1981 International Year of Disabled Persons,

Recalling also its resolution 32/133 of 16 December 1977, by which it established the Advisory Committee for the International Year of Disabled Persons, 33/170 of 20 December 1978, 34/154 of 17 December 1979, in which it, inter alia, decided to expand the theme of the International Year of Disabled Persons to "Full participation and equality", and 35/133 of 13 December 1980,

Deeply concerned that no less than five hundred million persons are estimated to suffer from disability of one form or another, of whom four hundred million are estimated to be in the developing countries,

Reiterating the continuing need to promote the realization of the right of disabled persons to participate fully in the social life and development of their societies and to enjoys living conditions equal to those of other citizens, as well as an equal share in the improvements in living conditions resulting from social and economic development,

Recognizing the observance of the International Year of Disabled Persons has contributed to the attainment of these objectives,

Recognizing also that a large number of disabled persons are victims of war and other forms of violence, and that the International Year of Disabled Persons has contributed towards the reaffirmation of the need for continued and reinforced co-operation among nations for world peace,

Believing that the activities undertaken by the international community in observing the International Year of Disabled Persons constitute a first essential step towards the achievement of the objectives of the Year,

Convinced that the timely and significant impetus generated by the activities of the International Year of Disabled Persons should be maintained and reinforced with appropriate follow-up action at all levels,

Taking note of the efforts of Member States during the International Year of Disabled Persons to improve the conditions and well-being of the disabled, Expresses its satisfaction at the convening of the World Symposium of Experts on Technical Co-operation among Developing Countries and Technical Assistance in Disability Prevention and Rehabilitation, at Vienna, Austria, from 12 to 23 October 1981,

Expresses also its satisfaction at the convening of the World Conference on Actions and Strategies for Education, Prevention and Integration, at Torremolinos, Spain, from 2 to 7 November 1981, organized by the United Nations Educational, Scientific and Cultural Organization in observance of the Year,

Taking note with appreciation of the progress made in the elaboration of a World Programme of Action concerning Disabled Persons,

Having considered the report of the Secretary General 77/ on the implementation of resolution 35/133,

Having also considered the report of the Advisory Committed for the International Year of Disabled Persons 78/ on its third session,

1. Expresses its satisfaction to all Members States which elaborated national policies and programmes for the implementation of the objectives of the International Year of Disabled Persons;

2. Takes note of the activities undertaken by organizations of the United Nations system and the relevant non-governmental organization in the observance of the International Year of Disabled Persons;

3. Urges Member States to make every effort to consolidate and build further on the results of the International Year of Disabled Persons in order to secure prevention of disability, rehabilitation and full integration of the disabled in the society and, in this respect, to consider maintaining, where appropriate, the national committees or similar bodies established for the Year;

4. Again invites Member States to submit national reports to the Secretary-General on their implementation of the Plan of Action for the International Year of Disabled Persons and, in particular, to consider elaborating, on the basis of their experiences, national long-term programmes of action in the field of disability;

5. Requests the Secretary-General to convene in 1982 a meeting of the Advisory Committee of the International Year of Disabled Persons to finalize the draft World Programme of Action concerning Disabled Persons, in the light of comments by Members States, international organizations and relevant non-governmental organizations, with a view to its adoption by the General Assembly at its thirty-seventh session;

6. Requests the Advisory Committee to consider at its fourth session the advisability of proclaiming the period 1983-1992 as the united Nations Decade of Disabled Persons and to submit its views to the General Assembly at its thirty-seventh session;

7. Requests the Advisory Committee to study the possibility of creating an optional international identity card for disabled persons with the purpose of facilitating the international travel of disabled persons;

8. Urges the Secretary-General to take the necessary measures to assure the successful follow-up of the International Year of Disabled Persons, in particular the finalization of the World Programme of Action concerning Disabled Persons;

9. Also requests the Secretary-General and heads of specialized agencies and other relevant organizations of the United Nations system to ensure necessary co-operation and co-ordination of their activities relating to the disabled;

10. Further requests the regional commissions to give high priority to the formulation and implementation of regional programmes related to equalization of opportunities for disabled persons, as well as prevention and rehabilitation, and urges the specialized agencies and relevant organs of the United Nations system to continue the implementation of such programmes;

11. Invites relevant non-government organization to continue and expand their programmes related to the disabled in order to maintain the momentum given by the International Year of Disabled Persons;

12. Welcomes the contributions made by Governments and private sources to the United Nations Trust Fund for the International Year of Disabled Persons and appeals for further voluntary contributions which would facilitate the follow-up of the year;

13. Calls upon the Secretary-General to use an appropriate portion of those voluntary contributions to support and strengthen activities in developing countries related to International Year of Disabled Persons, including the strengthening of organizations of disabled persons;

14. Urges the Secretary-General, the specialized agencies and other United Nations bodies and organizations to undertake or expedite the measures already under way to improve employment opportunities for disabled persons within these bodies at all levels and improve access to their buildings and facilities and to their information sources;

15. Invites Member States to promote close and effective co-operation between developed and developing countries through a transfer of technology and of the results of research and exchanges of information on the prevention of disability and the rehabilitation of disabled persons;

16. Also calls upon the Secretary-General and the heads of the specialized agencies to take all necessary measures to strengthen and expand technical co-operation activities in developing countries relating to the disabled, especially in the areas of prevention of disability, rehabilitation and integration of disabled in their societies, with particular emphasis on the need to develop and strengthen indigenous capacities and capabilities;

17. Stresses the importance of strengthening support services for the exchange of technical information and transfer of technology and know-how, as well as other activities for the development of technical co-operation in the fields of prevention, rehabilitation and equalization of opportunities in developing countries and notes with appreciation the offer of the Government of Yugoslavia 79/ to contribute in this direction;

18. Invites, as a matter of priority, Member States, organizations and bodies of the United Nations system, as well as governmental organizations concerned and mass media, to continue to undertake public information programmes, including the continuation of the present information activities of the Centre for Social Development and Humanitarian Affairs for the national committees, with a view to making all sections of the population increasingly aware of issues relating to the disabled;

19. Decides to include in the provisional agenda of its thirty-seventh session an item entitled "World Programme of Action concerning Disabled Persons" and requests the Secretary-General to report to the General Assembly at that session on the implementation of the present resolution.

APPENDIX 2:

RESOLUTION ADOPTED BY THE GENERAL ASSEMBLY
[on the report of the Third Committee (A/8588)]
2856 (XXVI). Declaration on the Rights of Mentally Retarded Persons

The General Assembly,

Mindful of the pledge of the States Members of the United Nations under the Charter to take joint and separate action in co-operation with the Organization to promote higher standards of living, full employment and conditions of economic and social progress and development,

Reaffirming faith in human rights and fundamental freedoms and in the principles of peace, of the dignity and worth of the human person and of social justice proclaimed in the charter,

Recalling the principles of the Universal Declaration of Human Rights, the International Covenants on Human Rights, 1/ the Declaration of the Rights of the Child 2/ and standards already set for social progress in the constitutions, conventions, recommendations and resolutions of the International Labour Organization, the United Nations Educational, Scientific and Cultural Organization, the World Health Organization, the United Nations Children's Fund and of other organizations concerned,

Emphasizing that the Declaration on Social Progress and Development 3/ has proclaimed the necessity of protecting the rights and assuring the welfare and rehabilitation of the physically and mentally disadvantaged,

Bearing in mind the necessity of assisting mentally retarded persons to develop their abilities in various fields of activities and of promoting their integration as far as possible in normal life,

Aware that certain countries, at their present stage of development, can devote only limited efforts to this end,

Proclaims this Declaration on the Rights of Mentally Retarded Persons and calls for national and international action to ensure that it will be used as a common basis and frame of reference for the protection of these rights:

1. The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.

2. The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.

3. The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his capabilities.

4. Whenever possible, the mentally retarded person should live with his own family or with foster parents and participate in different forms of community life. The family with which he lives should receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.

5. The mentally retarded person has a right to qualified guardian when this is required to protect his personal well-being and interests.

6. The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If prosecuted for any offence, he shall have a right to due process of law with full recognition being given to his degree of mental responsibility.

7. Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic review and to the right of appeal to higher authorities.

2027th plenary meeting,
20 December 1971.

1/ Resolution 2200 A (XXI).
2/ Resolution 1386 (XIV).
3/ Resolution 2542 (XXIV).

APPENDIX 3:

THE JOSEPH P. KENNEDY, JR. FOUNDATION

ESTABLISHED: In 1946 by Ambassador and Mrs. Joseph P. Kennedy, in honour of their eldest son who was killed in World War II.

OBJECTIVES :
- To seek the prevention of mental retardation,
- To improve the way society deals with its citizens who are already mentally retarded.

ACTIVITIES :

1. **Research, Treatment and Education:**
   Treatment of individuals with mental retardation has been the Foundation's top priority over the past thirty years. The Foundation has funded many centres for treatment, diagnosis and education of children and adults with mental retardation.

2. **Physical Education and Recreation:**
   The foundations main achievement was the creation of "Special Olympics Program", which gives retarded persons an opportunity for "normal" sports competition and development of more integrated social relationships.

3. **Family Programs:**
   To encourage parents and siblings to be involved in sports and recreation with their handicapped children, the Foundation developed a model program of physical activity and family play called "Let's Play To Grow". More than 100 "Let's Play To Grow" Clubs were established in 30 states in the USA and five other countries.

4. **Medical Ethics:**
   The foundation sponsored the first international symposium on medical ethics in 1971. It funded two major centres for bioethical study and established the Kennedy Inter - Faculty Program in Medical Ethics at Harvard University.

5. **Public Awareness and Recognition:**
   Kennedy Foundation maintains ongoing efforts to raise the public consciousness about persons with mental retardation - their rights, their capabilities and their needs - through speeches, meetings, interviews, workshops, articles and media appearances.

6. **Joseph P. Kennedy, Jr. International Awards:** Widely recognized as the "Nobel Prize" in the field of mental retardation, the Kennedy International Awards are given periodically to outstanding contributors in the categories of scientific research, services and leadership in this field.

7. **Public Policy in Mental Retardation:** The objective of this programme is to improve the standing of retarded people in the society through action research and programmes in the field of public policy.

8. **Aging and Mental Retardation:** The Foundation sponsored demonstration projects to meet the needs of persons with mental retardation who are aging.

9. **Other Activities:** Seminars, Lectures, courses and conferences in areas of special interest to the field of mental retardation are sponsored and developed by the Kennedy Foundation. Grants are given each year for medical research, demonstration and training projects. It also developed programmes for pregnant teens.

APPENDIX 4:

LEBENSHILFE (German Association for the Mentally Handicapped):

According to its constitution the National society for the Mentally Handicapped LEBENSHILFE (BUNDESVEREINIGUNG LEBENSHILFE FUR GEISTIG BEHINDERTE e.V. is an association of persons with mental handicap, parents and friends of the mentally handicapped, at federal level. This organization was founded in November 23, 1958 in Marburg/Lahn, and continues to maintain its head office there. Total number of members exceeds 100,000, of whom 45% are parents, and total number of employees in Lebenshilfe-facilities (teachers, educators, psychologist, social workers, doctors, technicians, administrators etc.) amounts up to 15,000. As parents' association the LEBENSHILFE acts, within the overall framework of services, as a pressure group representing and protecting the interest of the handicapped.

The overall programme established by 'LEBENSHILFE' in 1959 provides aid for the mentally handicapped from birth until death. It provides particularly for the following services and facilities:-

1. Multidisciplinary diagnosis and counseling services
2. Early stimulation and therapy (from birth till approx. 3 years of age)
3. Nurseries for pre-school children (ages: 3 - 6)
4. Special schools (6 - 18/21 years) and special facilities for profoundly, mostly multiply handicapped children, in as far as such children are not trained in special classes in schools for the blind, the deaf, etc.
5. Vocational training facilities for school leavers (2 stages), carried out in:
6. Sheltered workshops
7. A differentiated system of community-integrated living facilities (hostels) for those who cannot live at home,

also for the aged mentally handicapped
8. Organized leisure time facilities
9. Specialized social services
10. Residential facilities for those who cannot live at home or in hostels
11. Short-stay facilities for emergency situations in the family.

Principal sources of income are membership fees, fines, donations, small subsidy from the Federal Ministry of Youth, Family and Health, and sales of publications. Yearly local membership fee ranges from 12.0 to 60.0 DM.

The National society LEBENSHILFE is subdivided into 11 state associations and into 400 local and district associations. The state associations are incorporated associations as the National Society and the local societies. The State, local and district societies are members of the National Society as well as other natural and juridical persons to whom the National council has offered membership.

The organizational bodies of the National Society are:-

the Assembly
the Federal Board
the Council and
the Advisory Boards

The Federal Board has decisive rights, in particular regarding the annual budget and the exoneration of the council. Members of the Federal Board are the President by virtue of his office, two members of the council to be appointed by the council, and the presidents of all state societies.

The following services for the mentally handicapped are provided and directly run by the local societies:-

i. Centres and services for early help (0-3 years) of age;
ii. Special and integrated kindergartens (3-6 years of age;
iii. Facilities for moderately and severely handicapped children of school-age (16-18 years of age) either as private schools or as day-care Centre for limited period, sheltered workshops as well as hostels.
iv. The local societies also organize leisure-time activities, parents' counselling, fund-raising, public relations etc.

Services run by local LEBENSHILFE societies and local authorities are growing all over Germany. At present, total number of moderately and severely mentally handicapped cared for in day facilities are approximately 150,000 person. The following is a summary of number of faculties provided and the corresponding persons benefiting of these services:-

1. Day-care centres and special schools: approx. 600 (62,000 children).
2. Special kindergartens (partly run as integrated nurseries): approx. 350 (12,000 children).
3. Sheltered workshops: approx. 400 (80,000 adolescents and adults).
4. Hostels and group homes: approx. 450 (10,000 adults).
5. Early help services: some 450.

SCHEDULE OF ACCOMMODATION - HELP CENTRE, PHASE TWO:

1. Main Building:

	No. of Rooms	Unit Area
Entrance + Reception		
Fathers waiting room	1	36
Mothers waiting room	1	30
Social Worker office	2	15
Guest toilets		
Early Intervention	3	15
Multipurpose Hall		
Changing room "Boys"	1	60
Changing room "Girls"	1	60
Storage		
Audiology Department	1	
Computer room	1	15
Staff room "Male"	1	40
Staff room "Female"	1	40
Trainees room "Female"	1	30
Library	1	45
Teachers office	4	12
Medical Dept.:		
First aid room	1	10
Isolation room	1	10
Medical Examination	1	10
Psychological test room	1	10
Teaching aid room	1	45
Arts room	1	50
Music room	1	50
Training Kitchen	1	38
Sewing, knitting, handcrafts	1	50
Workshop for Boys	1	70
Laundry room	1	35
Wet room	1	35
Open Auditorium	1	35

2. Administration:

Meeting room	1	50
Supervisor + WC	1	45
General Manager + WC	1	42
Assistant GM	1	25
Secretary	1	12
Accounts	3	20
Personnel	2	16
Archives	1	50
Information System	1	25
Maintenance and Housekeeping	1	25
Security + drivers	1	25

Storage	1	25
Kitchen	1	16
Toilets	1	12

3. Satellite Areas:

Classrooms	20	56
+ Individual treatment room attached to each classroom	20	14
+ Toilet Unit (shared by 2 classrooms)	10	10
Teachers WC	5	4
Storage	5	6
Hall in each satellite	5	app. 70

4. Residential (Staff housing):

Category	Area of Units	No. of Units	No. of Bedrooms
A - "Management" (semi-detached villa)	140	4	3
B - "Educationalist" (self-contained flat)	68+10	20	1
C - Helpers "Education" (shared flats)	105+10	6	3
D - Support staff "Female" (shared flats)	105+10	2	3
E - Support staff "Male"	105+20	2	3-4

5. Other Facilities:

A - Cafeteria
"Staff dining room for 70 people"
Kitchen for 140 people + storage area + Nutritionist office
B - Nursery for staff infants
C - Swimming pool with a shallow end for physiotherapy
+ showers + shaded area
D - Maintenance and repairs facility

6. Others:

Main entrance gate, guards rooms, children zoo, playgrounds, snozelen, areas for planting outside classrooms, parking areas for guests, staff and residents.

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