The Handicapped Child: Current Concepts in Management and Rehabilitation

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Handicapped children are permanently impaired such that developmental potential is limited. Manifestations of handicap are varied, often multiple and include a wide range of body systems.

The disability process needs to be viewed as a "human condition" involving bio-psycho-social determinants and continuing the traditional module of illness to the points of impairment, disability and handicap. Defining these processes is essential in order to outline strategies of successful rehabilitative management. The role of a Child Developmental Institute for Neuor-Developmental-Behavioural Disorders is a valuable comprehensive centre of evaluation and multidisciplinary rehabilitation. In addition parental support and alliance in the therapeutic services play major roles. Institutional care sometimes becomes indicated.

(Egypt.J. Psychiat.,1992,15:96-101).

I. Introduction

When we speak of handicapped children we refer to permanent handicaps which impede the child's functioning in different ways and limit developmental potential. Handicaps may be temporary or permanent, visible or hidden, progressive or regressive.

* Manifestations of handicap are varied, often multiple, and may include: Mental retardation.

* Limitations of physical activity (as in Cerebral Palsy).

* Sensory deficits (visual and hearing impairment).

* Specific learning disabilities (other than those due to mental retardation).

* Communicative difficulties (speech disorders).

* Seizure disorders (poorly controlled cases).

* Conspicuous physical deformities (various genetic, dysmorphic syndromes or birth defects).

* Serious emotional disorders (childhood autism).

* Chronic physical illnesses (severe juvenile diabetes, cystic fibrosis).

The above listing covers main groupings but is not all inclusive. Combinations of handicaps are quite frequent. An excellent example is Cerebral Palsy, a disorder primarily of motor function, but among patients we see abnormalities of vision (25%), hearing and speech (greater than 50%), seizure disorders (33%), mental retardation (50-75%), learning disabilities (the vast majority) and frequently social and emotional problems (Balikov and Feinstein, 1979). In every sense, therefore, Cerebral Palsy conveys the concept of a multiply handicapping condition. The prevalence of disabilities depends on the broadness or narrowness of the definition and what conditions are included. Estimates have placed the figure at 10% of the world's population (broad inclusion of many disorders). Preliminary estimates from several developing countries suggest that at any given time 1.5% of the total popu-

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lation consists of disabled persons who could benefit from rehabilitation. (Bartram, 1987).

II. The Disability Process

To understand the handicapped child's "human condition" we must consider the bio-psycho-social determinants of the disability as well as the rehabilitative process. As in other areas of medicine, the traditional model of illness may be viewed in the following sequence:

Biologic/aetiologic factors ----> Pathology --------> specific manifestations of condition .

In this case, as with other illnesses, there is considerable interference with the individual's ability to discharge age-appropriate functions and social role. These latter interferences continue the sequence:

Illness -----> impairment ----> disability ----->handicap

It adds considerable delineation to the process to define the above terms. (Technical Report Series 668, 1981).

Impairment

In the context of health experience, an impairment is any loss or abnormality of psychological, physical, physiological or anatomical structure or function.

Disability

In the context of health experience, a disability is any restriction (resulting from an impairment) or lack of ability to perform an activity in the manner, or within the range considered normal for a human being.

Handicap

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, social and cultural factors) for that individual.

The individual limitation usually results from impairment and disability, but may be more the result of individual psychological factors, or social and environmental factors surrounding and responding to the handicapped individual.

Our mission as "healers" is to enhance the child's quality of life by maximizing inherent potential, independence and, where practicable, maintenance of as normal a life as possible, and "main streaming" into regular classes and activities when deemed possible, preferable and feasible.

III.Successful Management

A. General Considerations

Parents/family have the major responsibility for the care and nurturance of the handicapped child. This is often difficult and the physician needs to provide leadership and support enabling the family to meet their responsibilities. This includes clarification of diagnosis and degree of permanence, and finding appropriate medical and community resources to help maximize development of effective coping skills and happiness.

Comprehensive care is time-consuming. Clinical issues are often complex and do not lend themselves to direct or immediate intervention. Parents and physicians may not feel a sense of control, so necessary to avoid the anxiety of uncertainty. The physician needs to be satisfied with small gains and to see the value of support when nothing more dramatic can be done. Even with severely impaired children we are capable of bringing about a modicum of improvement because of recent developments of behavior ,modification techniques.

Families of handicapped children are burdened with enormous stresses which may be reflected in anger, uncooperativeness and lack of appreciation for efforts made on their child's behalf. Dealing with this attitude may be more time consuming for the physician than prescribing available interventions.

We must utilize and work comfortably with other health professionals and disciplines and community resources

while maintaining the leadership role of the primary physician.

As handicapping conditions are often permanent and stable, the long term outcome depends on social, academic and home adjustments which in the long run often are equal to, or of greater importance than the technical and medical procedures (Williams et al., 1991).

B. Diagnostic Assessment

Work-up of a child with a handicap includes traditional paediatric approaches with particular thought given to prenatal, perinatal postnatal, and genetic possibilities inherent in the different handicapping conditions. The range of investigative procedures is broad including physical, neurologic, haematologic, chemical, radiologic imaging and genetic chromosomal study.

The physician must explain to the parents what these procedures are designed to elicit. Because of the complexity of the studies he must maintain primary leadership and clarify the nature of the procedures and results in a clear, understandable manner. In depth clarification is best left for the ongoing questions posed by parents as they become less anxious and more settled in their coping capacities.

The physician should be comfortable expressing uncertainty in the midst of confidence, letting parents know that matters will clarify themselves over time, and that time does exist in these static, permanently disabling conditions.

C. The Role of A Child Developmental Institute For Neuro-Developmental-Behavioural Disorders

The comprehensive diagnostic evaluations usually called for in such children are ideally undertaken in a specialized child development institute capable of bringing together and blending the expertise of many needed professionals. This setting coordinates professional interventions thereby accelerating actiological clarification and determining the profile of the child's strengths and weaknesses. The team assessment approach ideally includes specialists from the following disciplines:

Audiology

Early Childhood Development.

Learning Disorder Specialists.

Nursing.

Physical Therapy.

Social Work.

Speech/language Pathologists.

Developmental Paediatrics.

Laboratory Services.

Neuropsychologists.

Occupational Therapy.

Clinical Psychologists.

Special Education.

The breadth of this diagnostic assessment lays the groundwork for rehabilitative planning which takes root early flows logically from the assessment process.

Such specialized child development institutes do not exist in all communities or in all nations. They represent an ideal, a standard for what is necessary for a community to plan and work toward in order to provide diagnosis and rehabilitative treatment for these complex, multifactorially determined disabilities.

Periodic re-evaluations are provided by these centres to monitor the child's progress.

D. Specific Approaches

Handicapped children often are deprived adequate opportunities for normalizing social and emotional experiences. These include cognitive learning, social and group experiences, and warm, stimulating parent-child interactions. A balanced parental approach toward limit setting is particularly vital to help handicapped children attain self-control mechanisms vital to personal happiness. Attachment needs of handicapped children are as necessary as, or more so, than of children without such limitations.

Involvement of parents and child (where appropriate) in decision making enhances compliance with the rehabilitative program.

The physician must interpret the child's condition and behaviour in clear, neuro-psycho-developmental terms to parents and other significant persons who have regular or occasional contact.

Parents must be helped to understand their own feelings which may be quite ambivalent and vary from overt hostility to gross indulgence. Such feelings are often quite threatening to parents and undermine their ability to effectively cope.

Parents' active involvement in the rehabilitative process is essential as through the feeling of competency can their self esteem be maintained. Initial parental reactions to the realization of their child's disability is often characterized by:

1. Disorganization.
2. Self-accusation.
3. Fear and anxiety about the future.
4. Denial of the problem.

These may attain overwhelming and disorganizing proportions. In time, with the physician reporting and communicating a genuine professional concern, parental defences become less brittle, more organized and increasingly constructive.

Siblings need to be considered as they too are deeply affected by the impact of an impaired sibling, particularly when the impairment is visibly apparent to their friends and the general community. In addition, it is inevitable that parental attention, either quantitative or qualitative, is deflected away from the sibling on to the handicapped child, especially early on. Their questions about the abnormal sibling should be answered simply and honestly in age-appropriate terms. This experience can lead to dysfunctional adjustment or may constructively teach tolerance, patience and understanding.

IV. The Role of Community Services

Availability of community services beyond diagnostic clarification is crucial. Most often the child's needs are multiple requiring some of the following.

* Adaptive equipment.
* Augmentative communication systems.
* Communication handicapped classroom.
* Head trauma follow-up program.
* Head motor skills program.
* Occupational therapy.
* Pre-school for children with handicapping conditions.
* Speech/language therapy.
* Amplification aids and rehabilitation for hearing impairment.
* Child and family counselling.
* Early intervention program.
* High risk newborn program.
* Neuro-developmental therapy.
* Physical therapy.
* Special education tutoring.
* Support groups for parents.

The Child Development Institute, discussed previously in the section on assessment, is once again an ideal, broadly based conduit for providing such diverse services and maintaining contact and communication with referring physicians, schools and community resources. This speaks strongly for the need of communities to establish these multidisciplinary centres.

Out of such centres have developed Early Intervention Programs. This is a comprehensive therapy program which serves infants and young children (birth to three years of age) with developmental disabilities. In center services include developmental evaluation by an interdisciplinary team and a therapeutic program including developmental therapies. Parent-group discussions provide oppor-

tunities to meet and share common concerns. A home-based component is provided for those children and families who, for medical reasons, are unable to attend the program at the institute. The aim here is to stabilize the disability and minimize handicap. Although there is no solid evidence that such programs bring about "measurable" effects, they clearly serve a humanistic purpose by providing structure and support to the child and family.

E. Institutional Care

When a seriously impaired child remains completely or mainly dependent on others for the long term, strain may become overwhelming and the question of suitability of institutional placement arises. The physician needs to feel comfortable in objectively discussing with parents the advantages and disadvantages of such a decision. It is generally believed that children have a better developmental future would they live in a home environment as long as possible. Parents generally feel more ready and comfortable about placing their child in an institution if they have given their all over the years on behalf of their child over the years and have established a good understanding of the permanence of the limitations.

A physician, convinced that such a solution would be beneficial to all, may diplomatically initiate such a discussion when the family appears reluctant to open the question.

There are of course very practical issues of availability of such settings, their appropriateness, quality and cost.

"We are guilty of many errors and many faults, but our worst crime is abandoning the children, neglecting the fountain of life."

(Gabriella Mistral, Nobel Prize winning poet from Chile).

V. Services For Handicapped in UAE

A complete listing of centres and services provided in the seven Emirates does not appear to exist at this time. Piecing together information indicates the following. There may be additional resources not described and the author would appreciate such information.

A. Child Development Institute For Assessment Of Neuro-Developmental Behaviour Disorders.

None existing. The work-ups for such children take place in hospitals usually under the direction of the primary care physician utilizing the specialty services of that hospital or referred to another where such services are available. The Sharjah City for Humanitarian Services is in the process of establishing a project of preventative, early intervention and assessment programs.

B. Training Therapy Rehabilitation Services

1- Sharjah City for Humanitarian Services (Sharjah) =

Mental retardation, cerebral palsy, hearing impaired, private, day program, limited dormitory.

2- Al Noor Center (Dubai)

Mental retardation, hearing impaired, private, day program.

3- Al Noor Center (Abu Dhabi)

Mental retardation, hearing impaired, private, day program.

4- Lanseef School (Dubai)

Mental retardation, hearing impaired, private, day program.

5-Handicapped Center (Dubai)

Mental retardation, cerebral palsy, visually impaired, government (ministry of labour and social welfare), day program.

6- Handicapped Center (Abu Dhabi)

Mental retardation, cerebral palsy, visually impaired, government (ministry of labour and social welfare), day program.

C. Special Classes Within Regular Schools

Mental retardation (or intellectual delay), hearing impaired, government, schools day.

Social workers are present in most schools and psychologists available for psychometric testing on a referral basis.

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L'Enfant Handicapé: Concepts Actuels de Prise en Charge et de Réhabilitation

Les enfants handicapés souffrent d'une limitation developementale permanente. Les systèmes atteints varient et sont souvent multiples.

Le problème posé par l'infirmité nécessite d'être considéré comme une condition humaine ayant des déterminations bio-psycho-sociales et faisant partie du module traditionnel de maladie allant du mal-fonctionnement, à l'infirmité ou l'handicape. La définition de ces processus est essentiel afin de délinier les stratégies efficaces de réhabilitation. Le rôle d'un institut de dévelopement de l'enfant en ce qui concerne les troubles comportementaux du dévelopement est essentiel afin de coordiner et d'évaluer la rehabilitation multi-disciplinaire, d'assurer la coopération parentale et d'offrir des soins institutionnels si necessaire.

المفاهيم الحالية لرعاية وتأهيل الطفل المعوق

تعتبر الإعاقة فى الأطفال بمثابة خلل مستمر فى مراحل ومناطق نموهم المختلفة والمتعددة، وتختلف الإعاقات من طفل إلى آخر إلا أنها فى الأغلب تكون متعددة وتشمل أجزاء ووظائف مختلفة من كيانهم وتهدف هذه الورقة إلى طرح مفهوم حديث لرؤية احتياجات الطفل المعوق من خلال اعتبار عملية الإعاقة المستمرة كحالة إنسانية تشمل الأبعاد الإجتماعية – النفسية – البيولوجية وتمثل استمراراً لنموذج المرض التقليدى الذى ينتج عنه الخلل وعدم القدرة والإعاقة. ويعتبر تحديد هذه المفاهيم ضرورى لرسم استراتيجيات ناجحة للرعاية والتأهيل، وتقوم مراكز ومعاهد تنمية الطفل لرعاية وعلاج الإضطرابات العصبية – النمائية والسلوكية بدور هام فى التقييم والتشكيل التأهيلى المتعدد النظم، وذلك بالإضافة إلى مساندة الوالدين وتقديم الخدمات العلاجية لهم ولأطفالهم