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Mental Handicap Under Five: To Young to Identify?

The quality of early intervention in the life of a child with mental handicap may be crucial in terms of later educational development. However, professionals need to be sensitive to the concerns, questions and reservations of parents at this most vulnerable time.

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THE CRITICAL DEVELOPMENTAL PERIOD

Children who are recognised as mentally handicapped, mentally retarded or who have severe learning difficulties under the age of five years are identified as pupils with special needs through the intellectual or social domain.

They also typically have some physiological and physical limitations due to a variety of prenatal and genetic conditions. Some of the most severely handicapped children show gross physical abnormalities and many clearly show some brain pathology. There are many conditions which underlie the aetiology of mental retardation and the causation and outcome are complexly and intimately interrelated. We know now that many forms of mental retardation are socio-culturally influenced, if not determined. As we have learned to use effective intervention procedures some potentially retarding conditions are avoided or are significantly ameliorated. The question then arises as to whether mental growth is inhibited, delayed or distorted by inappropriate or insufficient stimulation during a critical period of development, or is due to an indigenous characteristic. Aetiological and environmental factors are complex and obscure, but it is important to investigate both in order to further our understanding of their interrelationship.

It is only possible to make an aetiological diagnosis in about half of all cases of mental retardation, although more than one third of cases are attributable to genetic conditions. The development of language, perceptual speed, reasoning and motor ability are differentially dependent on both genetic and environmental conditions. After a medical diagnosis, the medical intervention can control or modify the many biochemical and metabolic contributors to mental retardation. The effects of prematurity, manutrition, and infection are clearly modifiable and even preventable. No child's condition can be seen as 'static' or fixed. The interaction of a basic condition is always relatively associated to the complex of accidental and deliberate environmental and interventional factors.

BELFAST SURVEY

In a recent study of families with young mentally handicapped children carried out in North and West Belfast, aetiological factors were the basis for further analysis and consideration. It was found that according to the parents, (N=60) the children's conditions could be variously classified as follows:

41% of the children had Down's Syndrome
22% suffered brain damage - cause unknown
15% were brain damaged related to post natal disease
11% had brain damage related to birth trauma
7% were handicapped due to genetic disorders
4% of the children were affected by the Foetal Alcohol Syndrome

The extent of the child's handicap was examined through the mother's report, as were the additional factors related to disablement. This showed that 44% of the children were non-ambulant and 96% of the children exhibited more than one difficulty. This is similar to other studies which indicate that most mentally handicapped children display a range of complex disorders which span the entire range of handicapping conditions through physical, mental and emotional disorders. Also 63% had problems with vision, 63% had problems with hearing and 30% suffered from epilepsy or fits. None of the Down's Syndrome children had epilepsy, but three children had serious heart defects and two had serious bronchial problems. The children's general medical and physical condition gave rise to a genuine concern about basic survival, as well as the increased certainty of vulnerability to disease and illness. The issues related to early diagnosis are affected by the causation and the time factors and responses to the initial identification of mental handicap.

PARENTS' QUESTIONS

The parents' accounts and their questions appear to centre around, the initial nature of the problem; from developmental delay, e.g. a child not sitting up at six months, or sensory disability e.g. hearing impairment, to a simple failure of the child to thrive, at the early stages. It is medical intervention that is called upon: it is the Health Visitor, the GP or the clinic doctor who is asked to examine the child and make a prognosis. Medical personnel make medical prognoses. The basic questions the mother wants an answer to are, "Will the child live?" "How long will she/he live?" "Will the child need medical intervention in the form of surgery or drugs?" "Is the child's condition treatable/terminal?" "Will I be given the appropriate agency, support and help to cope with my problems?"

The question of life and death, the basic survival chances and quality of life are the most central questions on parents' minds. Because of this concern, parents therefore are not immediately concerned about the relative merits/demerits of integrated or segregated school placement or about immediate and appropriate educational intervention.

NEED FOR PRE-SCHOOL CARE

The fact is that today in Britain 85% of children of three and four years' experience some form of pre-school provision, most of it part-time and some of it in primary school classes. Facilities for those children under three years and full-day care places for all ages are in very short supply, catering for less than 6% of children under five years (Pugh, 1988).

Most parents of mentally handicapped children develop an interest in early education in direct relationship to the degree of the child's medical condition. The parents of a Down's Syndrome child with moderate learning difficulties will be in a position to prepare and plan for the child's future education, whereas a mother of a recently identified severely disabled child will focus her concern more on the child's care.

DISTRUST OF PROFESSIONALS

The nature of the accounts alert all of us as professionals to the early experiences of parents with a mentally handicapped child. They show how the parents have been hurt, bewildered, misled and manipulated by different professionals related to young children with disabilities.

Parents who have had negative, or unreliable experiences of professionals associated with the child may develop either professional wariness or weariness.

The parents who learn to be wary of the 'experts' offering help and advice to them in the name of the child's handicap, will often appear aggressive, assertive, demanding or over critical of any services offered subsequently. These will be the parents who will question or attempt to challenge their child's initial school placement. They will question or demand pre-school provision.

The parents who learn to become weary of the 'experts' offering help and advice to them will appear disinterested, tired, impatient and passive. These will be the parents who will accept whatever initial school placement is offered. They will accept the absence or paucity of pre-school provision.

> They are not always aware of their basic rights and believe that early professional care is a privilege afforded to the 'few'. Sally Tomlinson (1982) states that "Professionals are outside and above the working class clientele who accept the mystique that professionals do possess superior ability and rational knowledge. Indeed professional powers and privileges depend upon this professional ability to create an aura of mystery around their work while at the same time selling their labour and conforming to bureaucratic principles. In the last century professionals could be described as liberal capitalists, they were not servants of the state. But nowadays doctors are largely employed by the state via the health services and psychologists and teachers are employed by the state via local education authorities". (p. 84)

NEED FOR A CO-ORDINATED APPROACH

Parents of a young mentally handicapped child may have had contacts with a Health Visitor, General Practitioner, a paediatrician, a psychologist, a speech therapist, a social worker, a physiotherapist, an occupational therapist and a specialist teacher before the child is assessed for the initial school or pre-school placement. The professional emphasis is of course, at present to develop a coordinated approach (see Pugh 1988) to the service provision for the under fives. However without the formulation of a policy for all under fives any provision lacks coherent aims for coherent development.

EMOTIONAL REACTIONS OF PARENTS

The parental confusion and dissatisfaction referred to earlier, is a reflection of the inter-professional confusion and difficulty to communicate. The parents are confused, upset and angry because of their treatment at the hands of professionals. Like all human beings the retarded child does not live in a vacuum. She or he needs close emotional relationships with others, and these relationships must be satisfying and stress reducing if the child is to achieve maximum potentialities. The relationships between the parents and their child are of great importance. If the parents exhibit negative reactions to the child's disabilities then it becomes more difficult for healthy relationships to be established. The greater the negative emotional reactions of the parents, the less likely it is that the child will achieve the level of emotional maturity he is capable of attaining. Therefore the negative reactions of the parents can adversely affect the full maturational development of the retarded child. Many of the early accounts uncover the frustrations and negative memories which the parents associate with their attempts to understand their child's disability and their attempts to accept help during this quest.

The parental reactions to the child are influenced by the emotional climate of confusion and insecurity. The emotional reactions of the parents may transfer to the child in the form of anxiety, resulting in undesirable social behaviour. The welfare of the child depends in large measure on the well-being of the parents, which ultimately affects the entire family group.

Regardless of the basic cause of the handicap the parents' concerns about the child, the guilt, anxiety and caring in terms with the handicap as well as the daily coping with the child, all take a considerable emotional toll on the parents. The professional delays, withholding of information and lack of coordinated service provision all add to the parental overload.

EARLY EDUCATIONAL PROVISION

Early education for the mentally handicapped child differs from that of the ordinary child. Once the handicap has been confirmed by medical professionals, early provision may be offered in either:

(a) A specialist nursery.
(b) An integrated nursery
(c) An alternative setting through home teaching e.g. Portage.

The child who attends the specialist nursery will, during the pre-school education period, be subject to an educational assessment through the school's Psychological Service. It is therefore when the child reaches his/her fourth birthday that this mechanism becomes operational. The majority of these children through their early placement and subsequent assessment, transfer to schools for children with severe learning difficulties. Children who may be accepted at an integrated nursery or who receive home teaching have more options related to initial school placement. The nature and severity of the handicap may be modified through social interaction in (b) or through individualised teacher and parent teaching as in (c). Again the early environment, either social or educational may limit or extend the child's potential.

The forms of educational provision offered to the children are scarce and under-resourced and the different traditions they embody tend to reinforce the existing divide between education and care.

PRE-SCHOOLING AND POSITIVE COGNITIVE DEVELOPMENT

A study carried out by Osborn and Milbank in 1987 which was a sponsored Report from the Child Health and Education Study, has provided conclusive evidence that pre-school education provided in nursery schools and playgroups can have a positive effect on the cognitive development of the children who attend them. The actual type of pre-school experience matters very little provided the child receives proper care, has interesting activities and other children to play with.

Has this finding implications for the specialist nursery and for children who are considered mentally handicapped at a very early age before they have the opportunity for social development through fully integrated pre-school experiences?

PRE-SCHOOLING AND SOCIAL DEVELOPMENT

The 1987 Report also found social and family factors exerted a powerful influence on the child's educational attainment, and of these, parental interest in the child's development was one of the most important. The reason is that strong parental interest in the child's educational progress was likely to enhance that progress and was linked to more positive parental efforts to seek appropriate pre-school placement. This early interest is subsequently linked to the child's later attainment at 10 years of age. The mother's involvement in the pre-school institution which the child attended was also said to enhance the child's educational achievement.

In Dublin there is an excellent pre-school service for the under-fives in St. Michael's House. In their education and care of handicapped children there is a comprehensive and structured programme involving the parents, which reflects much of the understanding of Roy McConkey and others. However in North and West Belfast there is a high incidence of mental handicap, but there is no specialist pre-school provision, and ordinary nurseries already have such a high number of social problems, their quotas are full. Many children are transported to the only specialist pre-school provision for children with mental handicap in Northern Ireland ie the MENCAP Nursery Unit at Segal House in South Belfast.

There are numerous varied clinics for medical support of children and two specialised clinics offering assessment and emotional support for children and parents, however the professionals themselves indicate that they don't believe that this is enough and that there is professional overlap and blurring of roles and boundaries as one states: "Professionals should get together for the long-term good of mother and child".

PROFESSIONAL CONFLICT AND THE NEEDS OF THE CHILD

Yet is is also clear that the professionals aim to improve inter-professional understanding, with the ultimate goal of better service delivery to the public. Professionals do argue among themselves and engage in power struggles. These have been the subject of several studies by sociologists, a recent one being Tomlinson's (1982) study of childrens' admission to special schools. She was highly critical of the way in which, in her view, professional infighting and power struggles get in the way of helping the child. The Portage scheme in North and West Belfast was reported during an interview with the main coordinator to;

> ".....have its fair share of teething problems, particularly from other professionals rather than parents - it is seen as a threat to Health Visitors, Social Workers, Physiotherapists, etc."

A certain degree of professional conflict is seen as healthy, an irritant in a stable system resulting in exciting change and innovation. It can also be a thorough nuisance, reducing effectiveness and impairing service delivery. Circular 3/74 on Child Guidance Services (DES, 1974) recognised these problems and the changing interprofessional relationships and argued for a 'network' approach to services. In this form of service delivery, the professionals are seen as autonomous (not answerable to colleages from different professions). Colleages from different disciplines contribute to discussion of, and decisions about children, different professionals taking the lead at different times depending on the problem without an inevitable hierarchical relationship. 'Professionalism' is an important and complex issue which because it has largely been produced by the historical development of the professions (Potts 1982) will not be easily eliminated.

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