HANDICAPPED CHILDREN AND HANDICAPPED FAMILIES

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This article is concerned with the interaction between children with an obvious handicap and their families and its result on them both, with a discussion of some parent-oriented assistance programs.

A handicap is any condition which results in the person being placed at a disadvantage in coping with and solving the problems of socialization, school, work and independent living. Whether the handicap becomes a disability depends on the nature of the handicap, the demands made on the person and the assistance received. When a person is unable to cope or requires a great deal of extra assistance in coping with the demands of everyday living, then that person is disabled. Some examples of the most common types of disabilities are mental retardation, blindness, deafness, and cerebral palsy. In this article most of the focus is upon mental retardation which has been the subject of many studies.

A handicap may be prevented from becoming a disability, or the amount of the disability may be limited, by alterations in the individual. For example, a reading disability may be prevented by the child receiving remedial reading instruction, or a visual handicap may be corrected with glasses. Another way of compensation is to alter the demands made of the person or to alter his environment. In this fashion an environment is created with which the person can cope, that is his own adaptive environment, for example, by providing ramps for persons in wheel chairs. Also, the handicapped person may cope by receiving extra assistance from others in selected activities. For example, an individual previously classified as retarded in a school setting may be able to cope in the adult world of work and living provided someone - the "citizen advocate" role of Wolfensberger and Zauha (1973) - helps with the more difficult tasks, such as credit buying, banking and finding a new job or place to live.

The handicapped child has a great impact on the family, and in turn whether the handicap becomes a disability and to what degree depends in part on the family.

Original Family

A family is made up of individuals each with their own characteristics and past history. Their characteristics will influence how they cope with
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a stress such as having a handicapped child. In addition, the emotional and educational atmosphere of the home is a reflection of their past experiences and present situation. The following are some of the important factors which influence the family's reaction to a new handicapped member: the presence of one or both parents in the family, the parents' expectations for themselves and their children, their physical and emotional health, and their socio-economic situation.

**Handicapped Child**

The characteristics of the handicapped child will affect the degree of stressfulness as perceived by the parents. For example, the type of condition is important (Freeman 1967) as the stress involved in mental retardation varies from that of epilepsy which is acute, periodic and unpredictable, to that of Tay Sachs' disease in which the condition is deteriorating, leading to death. Another characteristic which can add stress to the family is the child's appearance, which may be unusual as in Down's Syndrome, and certain congenital abnormalities, such as thalidomide limb malformations. This abnormal appearance will arouse comment by others and be contrary to parental expectations.

The amount of extra time and effort required of the mother in child care and supervision, for example the increased time needed to feed a child with a cleft palate and the extra supervision and care required because of the prolonged immaturity of the mentally retarded child, adds to the stressfulness. Another example is the increased need for parental vigilance of the child with serious seizures.

The inability of the child to compete with others and the frequent rejection of his efforts at socialization place an added load on the family. This is seen with the retarded child who continually finds himself out-of-phase with his peers; for example, when he is developmentally able to play a simple game of catch, others of his age want to play baseball for which he does not yet have the necessary skills. Because of this reduced amount of peer involvement, the parents find the handicapped child requires more of their time to entertain and supervise than the usual child. These additional demands placed on parents may be further increased if the child's condition is complicated by frequent illnesses, such as respiratory infections in Down's Syndrome.

In short, the care of a handicapped child is a much more demanding job than that of the usual child and requires more of the parents every day.