

IMPORTANCE OF FAMILY THERAPY IN DISABILITY REHABILITATION

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ABSTRACT

Disability is defined as a physical or mental condition that limits a person's movements, senses, or activities. The birth of a disabled child can be experienced by parents as a loss of the anticipated 'healthy' child. This bereavement can be a lifelong issue that becomes reinforced at various life stages and by the individual's inability to fulfil the 'normal' expectations of our culture and society. Recent studies have demonstrated that there are parental needs at the time of presentation of diagnosis that are not being met. One reason why intervention with the family of a child with a disability is so important is that the child's adjustment and rehabilitative progress is affected by the family's strengths, weaknesses, and emotional reactions. Being sensitive towards the practical problems of these parents and helping them by giving certain factual information on disability & rehabilitation would make a positive effect not only to the child with disability but also to the family members.

INTRODUCTION

Disability is defined as a physical or mental condition that limits a person's movements, senses, or activities. The most commonly cited definition is that of the World Health Organisation in 1976(1), which draws a three-fold distinction between impairment, disability and handicap, defined as follows. 'An impairment is any loss or abnormality of psychological, physiological or anatomical structure or function; a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being; a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that prevents the fulfilment of a role that is considered normal (depending on age, sex and social and cultural factors) for that individual'.

Rehabilitate in Latin "habilitas" means to make able. A dictionary meaning says that "return or restore to previous state or condition". Rehabilitation is the process of helping an individual to achieve the highest level of function, independence, and quality of life possible. Rehabilitation does not reverse or undo the damage caused by disease or trauma, but rather helps to restore the individual to optimal health, functioning, and well-being.

The importance of Family care in Disability Rehabilitation

Research has shown that family carers support over 80% of people with a disability and that family care remains the predominant type of care until middle age. Professional, social and political systems need a greater depth of understanding and empathy for the needs of family carers than they have at present. Accounts of families' experiences frequently contain examples of unsympathetic and unhelpful interventions from professionals, which may add further to family stress. Families vary enormously both from one another and over time; the emphasis should therefore be on understanding processes rather than categorical facts, and generalizations are best avoided. This contribution discusses intellectual disability, although many of the concepts and conclusions apply to a range of chronic disabling conditions.

Historical Perspectives

Until the 1950s, the birth of a child with a disability was seen as a tragedy for the family, without hope of resolution or adaptation, a view that stigmatized the child, the mother and the family. Within this context, institutional care was seen as a way of preventing the child disabling the family. Such views are unacceptable now, but they

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illustrate that the early research into family functioning was based on a pathological model of adaptation, and that inferred maternal psychological reactions were equated to family functioning. Mitigating or mediating factors within the family or society were not felt to be relevant given the tragic nature of the birth, thus ignoring the positive adaptations that families made.

Family Relationships

The birth of a disabled child can be experienced by parents as a loss of the anticipated 'healthy' child. This bereavement can be a lifelong issue that becomes reinforced at various life stages and by the individual's inability to fulfil the 'normal' expectations of our culture and society. Siblings may also be affected, experiencing difficult and conflicting emotions such as loss, resentment or guilt.

Many people with disabling conditions live with their own families, and most others live in family-type groups such as group homes or hostels. In spite of this, little has been published about family and systemic work, although these models are influential. Concepts of 'loss' may need to be worked through at various stages of the family life-cycle, such as loss of the 'normal' child or sibling, or loss of aspirations for the individual's future development. The roles assigned to members of families are often the source of difficulty or dysfunction. A person with learning disabilities may be expected to be inept or incapable in all circumstances; or they may be seen as 'special' or a family 'pet'. They may fulfil a role that keeps family or parental relationships intact or provides a focus for dysfunction.

Diagnosing Disability in Childhood

A disability may be recognized at any time in childhood or adolescence, but generally the more severe the disability, the earlier it will be noticed. Children with Down's syndrome are usually diagnosed soon after birth because of their physical characteristics, whereas those with a mild intellectual disability and no physical differences may not be diagnosed until they start to experience difficulties in later years.

Current studies have demonstrated that there are parental needs at the time of presentation of diagnosis that are not being met. One reason why intervention with the family of a child with a disability is so important is that the child's adjustment and rehabilitative progress is affected by the family's strengths, weaknesses, and emotional reactions.

Reactions of Parents

Parents' reactions after learning of their child's disability may be better understood by regarding some of the usual thoughts and expectations most parents have while preparing for parenthood. The typical parent, while looking ahead to the birth of a child, fantasizes about and forms images of the expected infant.

Parents, especially mother might initially express denial, feeling of anxiety, thoughts of being trapped and feelings of "why me?". All these might eventually lead to depression and a lasting feeling of guilt about the inability to deliver a non-disabled child.

Family's & Society's Reaction

Other members of a typical family, especially in rural areas of the country tend to blame the parents, (especially the mother) for delivering a child with disabilities and view it as a medical problem. They urge them to consult different doctors and when there is a failure to get a cure for the problem, the family members come to a conclusion that the parents have not taken any interest to the child's condition. Their society might criticize, looks down, Mocks / makes fun or treats like untouchable to the parents of children with disabilities. On the other hand some family members might express too much of concern and sympathy towards them.

Practical problems faced by Parents in the Management of a Child with a Disability

For a parent of a disabled child the day to day life is a continuous struggle and they are not sure about the nature of the problem waiting for them for the next day due to the unpredictability of the disease or disability. They might experience

sleep disturbances or lack of deep sleep due to the care giving to the child during night hours. The physical burdens related to dressing, lifting, feeding, and extra housecleaning is another hardship for them. Added to it, they amount to financial stress and strain because of continuous medical expenses or rehabilitation program which makes the situation worse.

Finally they refrain themselves from their original community / society and keep off from social gatherings due to the feeling of helplessness, reduced self esteem, resentment over excessive demands of time, money and other burdens.

Dealing with Family

“Empathy is the key” to deal with parents of children with disabilities. It is very important to understand where parents are and the emotions they are experiencing. They're broken-hearted. It's going to take them a while to figure out the impact of their child's disability on their lives. Explain them that how their infant is difference from other children.

Let parents know the facts of the disability conditions. Explain the parents that their child's condition is not caused by any of their sins or wrong deeds. Disability is not a disease / illness that had to be cured rather it is a condition which needs to be managed / improved. Explain them that Continuous Rehabilitation Program will make significant changes in the child's condition and Improvement includes from activities of daily living (ADL) to Independent living. Let them know that more the input is the best the outcome.

One need to be mindful of individual differences. Each person and family are different. The more fragile the child's condition, the more emotionally fragile the parents are. Make sure to gauge just how much information parents are ready for and offer only as much as the parents

can handle at that time. Ask a lot of open-ended questions, such as: 'How can I be of service to you?' or 'What are your goals, at this point for your child?'

Let parents know what they find lovable and exciting about their child. Ask them about their happiest moments and help them hold on to these moments and build on them. If parents are having trouble playing with their child, you can model appropriate techniques and activities for the child's developmental level. Help the parents to deal themselves and to ignore the society's criticisms.

CONCLUSION

Research on families and disability has grown apace and with it the reasons for family research, which are significant for professionals. The implications for practice and support are important - many families have said that, too often professionals fail to inform them or value their opinions. Many interventions add to the difficulty of the adaptation families need to make is also a matter for concern. The research increasingly reflects the complexity and variability of family life; although difficult, it is preferable to overcome former pathological models of family functioning.

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