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Abstract

This short article lists the common patterns of stress experienced by families who have a child with a disability. The author explains some of the reasons which underpin these patterns which include our tendency to experience our children as extensions of ourselves and the belief that finding fulfilment through a child must be abandoned when our child has a disability. The paper is an excerpt and does not go on to include ways of overcoming these stresses.

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PARENTAL REACTIONS AND CONFLICTS

The following was taken from the article entitled "Parents of Mentally Retarded Children - Misunderstood and Mistreated." by Phillip Roos, from the book Parents Speak Out. Views from the other side of the two-way Mirror. AP & HR Turnbull, Charles E Merrill Publishing Co, Ohio. 1978.

In a society such as ours, which greatly values intelligence, intellectual disability is a formidable handicap. The tendency to equate humanness with intelligence is common, and the perception of the disabled person as subhuman organisms is still prevalent (Wolfensberger, 1969). Hence most parents - though well adjusted - faced with having an intellectually handicapped child are likely to experience major psychological stress.

Roos identifies common patterns of stress:

1. LOSS OF SELF-ESTEEM Because of our tendency to experience our children as extensions of ourselves, a disabled child is likely to threaten our self-esteem. We may question our own worth and abandon some of our long-range goals when it becomes obvious that our child will be unable to achieve as we had hoped.
2. SHAME While most parents take pride in their children's accomplishments, parents of an intellectually disabled child learn to anticipate social rejection, pity, or ridicule. Their love of their handicapped child is only a partial protection against the feelings of shame generated when their child is pointed out as deviant or when other children laugh at him/her.
3. AMBIVALENCE The mixed feelings of love and anger typically experienced by parents towards their children is usually greatly intensified towards an intellectually disabled child. The greater the frustration generated by the disabled child's irritating behaviour and failure to learn, the more likely are the parents to feel anger and resentment. Fantasies of the child's death are not uncommon. Since these feelings are typically accompanied by guilt, some parents may react with overprotection while others tend to reject their child.
4. DEPRESSION Most parents are deeply disappointed in having an intellectually handicapped child and realistically concerned with the future. To some, intellectual handicap symbolises the death of the child and may lead to the type of grief reaction associated with the loss of a loved one. In any case, chronic sorrow can be anticipated as a reaction to having a disabled child.
5. SELF SACRIFICE Some parents seem to dedicate themselves totally to their disabled child, make great personal sacrifices, and adopt a martyr-like approach to life. Sometimes this pattern leads to family disruption, including neglect of other children and marital conflicts.
6. DEFENSIVENESS Professionals are familiar with parents who have become hypersensitive to perceived criticism of their disabled child. Often these parents respond to inferred criticism with resentment and belligerence. In extreme cases, parents may deny that their child is intellectually disabled, rationalise his/her shortcomings, and seek professional opinions to substantiate their own conviction that there is really nothing wrong with their child.

Roos also states that parents of intellectually disabled children have concerns and anxieties not related to their disabled child, but which are exacerbated by the situation - old conflicts and anxieties being "reactivated". Professionals, Roos claims, prefer to discount or neglect these conflicts, possibly due to their own discomfort or feelings of inadequacy in the situation.

The most crucial conflict areas, which are most likely to be reactivated at having an intellectually disabled child, include:

1. Disillusionment As children we are taught to develop totally unrealistic expectations, such as success, achievement, wealth, love and status. We expect wise parents, loving and loveable mates, and perfect children. Experience gradually erodes these unrealistic expectations of us and others leading to a long series of disillusionments in us, in others and in life in general.

Many of us channel our frustrated yearning for perfection into our children, through whom we hope to realise our thwarted dreams of accomplishment and happiness. Unfortunately, an intellectually disabled child is usually an unsuitable vehicle for fulfilling these hopes, so s/he represents a major disillusionment - often the culmination of a long series of disappointments. If the parents do not have other children, the possibility of them finding fulfilment through their children must be abandoned. Parents may then desperately search for other avenues to self-enhancement, or they may slip into pervasive feelings of hopelessness.

2. Aloneness The need for intimacy seems to be universal, but no one can transcend his individual boundaries and fully share his feelings and perceptions with another. Often the last desperate hope of overcoming aloneness is through our children - products of our bodies, shaped into our image, literally extensions of us. But a disabled child may not be able to fulfil this need because of limited capacity to communicate and to achieve intimacy. The parents of such a child may feel that they have lost their final chance to achieve intimacy and may become overwhelmed with feelings of aloneness.

3. Vulnerability Most of us begin life with the fantasy that we are all powerful. As we mature, we learn to recognize our own helplessness and gradually recognize that others, too, are not omnipotent, including parents, teachers, and heroes. Pain, injury, illness, and failure repeatedly confront us with our personal vulnerability, the tenuousness of our control over the world, and indeed the fragile nature of life itself. Intellectual disability in one's child reactivates these feelings of vulnerability. We are painfully reminded that our most precious possessions, our dearest dreams, can be completely destroyed and that we are helpless to do anything about it.

4. Inequity Our nation is founded on the principle of justice for all, and we are taught from earliest childhood that fairness and justice ultimately prevail. "Good" will triumph, and if our judicial system falters, some greater force will reward heroes and punish villains. When faced with disability in his/her child, a parent may feel overwhelmed with the enormity of the apparent inequity, and the natural reaction is to ask, "Why me?" In trying to answer this question, the parents may conclude either that they may deserve the punishment because of grievous sins or that the world is neither fair nor just. The former alternative leads to guilt, remorse, and self-recrimination; the latter threatens basic ethical, moral, and religious beliefs.

5. Insignificance Young children typically imagine that they are important figures occupying a central role in the scheme of things. Maturity brings with it the realisation of personal insignificance, yet most of us are raised to yearn for greatness or, at least, meaning. When greatness escapes us, we search for meaning in filling satisfying social roles, such as those of husband, wife, mother etc. When we are frustrated in achieving a rewarding parental role - as can easily occur with a child with a disability - we are vulnerable to feelings of insignificance by being deprived of an important opportunity to achieve meaning.

6. Past Orientation Most parents anticipate their child's future with enthusiasm, expecting such happy events as scholastic achievement, success in sports, promising careers. In contrast, parents of an intellectually handicapped child usually view their child's future with apprehension, anticipating scholastic failure, and exclusion from services (educational, social, and recreational), inability to live independently, and a life of loneliness and isolation.

Realistically, services tend to become less adequate as the disabled child ages, increasing the parents' frustrations. Hence, while most normal people are future-oriented, parents of a retarded child tend to retreat from the future as a source of pain and shift towards past orientation and from an optimistic to a pessimistic attitude towards what lies ahead.

There are four main crises in the lifespan of the disabled person and his/her family:

- (a) when the existence of the disability is recognised
- (b) when any education or schooling programme is considered
- (c) when the child leaves school and emerges from an often protective environment into the 'real world' with its problems of employment, sexuality and marriage.
- (d) when and if the parents feel they are no longer able to have their disabled child living with them.

A MAJOR SOURCE OF STRESS FOR THE FAMILY IS THE CONTINUITY OF SOME OF THESE ISSUES.