

# PARENTING A HANDICAPPED CHILD

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## Introduction

It is difficult to understand the full impact of a handicapped child upon a family. First we must have some understanding of the impact of a healthy child upon the lives of his parents and siblings. The meaning of parenthood and the expectations and goals of each parent includes the joy of giving, of sharing, of watching and re-experiencing the mystery of life unfold before their eyes and the feeling that comes with knowing that they are part of it. However, along with this there comes a constant drain of energy and emotions, self-doubts regarding discipline, health concerns, frequent exasperation and loss of patience.

The raising of a healthy child puts a demand for stability and maturity upon each parent, the need for economic security, a family structure based upon mutual respect, easy communication, and clear guidelines for decision making, as well as the assistance of the outer greater society with its time-honored institutions, churches, medical and recreational facilities to help the growing child along the developmental milestones to that day when he, too, can become an independent contributor of the society in which he lives.

But what of the child who is born "different," whose intellectual and physical handicaps delay or prevent his smooth transition along the developmental chain to maturity and independence, a child where the usual guidelines and supportive services to integrate him into society are lacking?

The handicapped child is not only physically or mentally disadvantaged, but socially excluded, physically deprived of the opportunities for exploration and the new experiences open to his siblings. He or she is also at high risk for an unnatural mother-child relationship which could further increase his inhibition, dependency, and disturbed self-concept.

This is an attempt to clarify some of the complex factors modifying the impact of the retarded child upon his family in order to help their parents as well as to provide suggestions for therapeutic intervention by new professionals entering this field.

Every delay in an infant's development based upon customary standards for bowel training, walking, talking, height and weight, is a source of mild to progressive anxiety on the part of the parents. But because there are children who, for various reasons, have delays in these areas but nevertheless eventually catch up to their peers, the average parent will tend to go into what has been labeled as "cognitive dissonance", which is a form of denial that lasts well beyond concrete evidence that their child has serious problems. The real psychological crisis occurs only at the point where the diagnosis of "mental retardation" is made by the pediatrician and finally accepted by the parents.

Now, the entire value system of the parents, which tends to be based upon the value system of our society that worth is commensurate with high achievement and capabilities, must undergo a major change. This is especially true if this is the couple's first child and they feel the loss of their expectations of creating together a healthy family.

Also missing are the instinctual responses that newborns have of smiling and glee when receiving attention and nurturance. Parents feel considerable inner conflict regarding their accepting or rejecting of a child who had been an object of love and a source of high future expectations. Farber (1959) described how parents suffer what he terms "career frustration" at the point of realization that their child is mentally retarded. This is commonly followed by a period of depression that may be expressed as "living in a void," or "there's nothing to live for now."

All of the family members must reorient their lives with respect to a severely handicapped child. The search begins for services, advice, and support. The usual pattern is for the child's pediatrician to refer the family to one of the large diagnostic clinics in a major city. Here the child undergoes extensive physical, neurological, and psychological testing, along with expensive laboratory procedures that now include genetic testing.

However, whatever hopes the parents may have had from this expenditure of professional time and energy is usually short-lived. It is not unusual for parents to be told of their child's handicap in diagnostic terms such as cerebral palsy, encephalopathy, autism or congenital abnormality, which still leaves many questions unanswered. The child is then referred back to the referring pediatrician who is often not equipped to handle the child's problems within a busy office practice outside the fringe of his specialty.

Many of the parents' important unanswered questions include:

- What is the cause of our child's retardation?
- Have we personally contributed to his condition?
- Is the condition hereditary?
- How shall we explain him to our children, friends and neighbors?
- Will our child ever walk, talk, be independent?
- Is there a drug or operation that might brighten him up?
- What resources are available for help? And can we afford it?
- What will be his effect on our other children?
- What will happen to him after we are gone?

Parents need constructive answers to these questions in order to prepare themselves psychologically and emotionally for the stresses ahead and to make realistic decisions based upon their existing economic and physical resources.

Future planning is impossible without some estimation of the life expectancy and the ultimate level their retarded child will be able to attain in the areas of social adaptability and independent living. Lacking appropriate answers to their basic questions, parents tend to proceed on a confused day-to-day basis trying to cope piecemeal with each crisis as it occurs while developing often unhealthy defenses to help them to weather a turbulent sea of inner anxiety and periodic swells of desperation.

A retarded child who appears early in the marriage of a young couple may have an especially deleterious effect upon the family by curtailing the desire of the parents to further increase the family size, by severely restricting the family's recreational and social activities, and eventuating a general family withdrawal from community life. For these reasons, divorce is twice as common in marriages in which there is a handicapped child.

#### EMOTIONAL REACTIONS AND DEFENSE MECHANISMS OF PARENTS TOWARD THEIR RETARDED CHILD

Parents react to the birth of a “defective” child with shock, disbelief, anger, disappointment, despair, and grief. This response may be intensified by the way in which they are first informed of their child's low intellectual potential. The time when the news is first received is also important.

The diagnosis of mental retardation is often missed during the first few years unless it has a fairly obvious organic etiology. For one thing, there is a reluctance on the part of the physician to commit himself to this diagnosis as there still exists a pervasive feeling of pessimism among professional people regarding mental retardation. This is often related to a lack of knowledge of available treatment facilities and the physician's own feelings of helplessness and inability to offer constructive advice and support.

Parents develop a variety of defenses in order to deal with this unexpected situation in which they find themselves. Many of these defenses are harmful in that they prevent the parents from viewing their problems realistically and only lead to further grief in the long run. Most parents are unwilling to accept the diagnosis of mental retardation, preferring to find a physical or emotional reason for their child's slow development.

There also seems to be a more ominous stigma placed upon the child if he is "born that way." Sometimes parents use massive denial upon hearing of the news. They might insist that they were never told that their child was retarded despite the fact that several physicians had indicated this in the past. The chief complaint is rarely, "My child is mentally retarded." Rather there is some euphemism about delayed or poor speech for not keeping up with siblings. Fathers sometimes comment, "This is the way I was when I was his age."

Sometimes what the parents are told may represent the physician's own subjective upper-middle-class attitudes toward mental retardation as an intolerable deviation within the context of our present social structure. When I was the medical director of the new George Miller Jr. Centers for Multi-handicapped Children and Adults in California, I often attended breakfast meetings with local pediatricians. Their general attitude at that time was, "Since the child is never going to be able to be an engineer, a teacher or a doctor, the mother should send the child to

Sonoma State Hospital and forget that she ever had it.” That was the common practice at that time. However, most mothers are not capable of forgetting their child and commonly developed a syndrome of, what had been described in the literature, as “Chronic Sorrow.”

However, it was a delight to witness how parents, once adequate facilities were made available in the community, are able to form cohesive support groups that reduced considerably their stress and the stigma of having a handicapped child.

Often, parents are intellectually able to accept a son's diagnosis as retarded, but continue to react emotionally to the child as if he were not retarded and persist in maintaining unrealistic expectations. This defense has been described as "cognitive dissonance," in which the parents, unable to emotionally accept the facts, may continually find fault with the school system, keep seeking new treatments and new medications to cure their son's condition, or pounce on the son, himself, with anger and scolding because of his "disobedience" in not performing up to standard.

When it comes to the actual handling of their child, parents react in different ways. Some may avoid direct contact with the retarded child and handle him as little as possible. Others, without deliberately rejecting the child, may detach themselves emotionally while simultaneously assume responsibility by compulsively organizing their lives around a ritualistic schedule of care with emphasis upon cleanliness and antiseptic conditions.

They may tend to focus upon the child's defect rather than to perceive him as a whole person, and are often surprised later to learn that their child has many things in common with other similarly handicapped children, that someone understands and is able to redirect the aberrant behavior of their child and, sometimes, by how much their child is actually capable of learning from special teaching.

Parents need recognizable feedback from their children to reinforce their continuous expenditure of time and energy. The prolongation of dependency of the retarded child, along with his need for almost an almost constant commitment of parental support, gradually forces the coping defenses of some parents to take on a more chronic aspect of developing an unhealthy parent-child relationship, with the mother tending to orient her routine exclusively to the needs of the child.

Overprotection and infantilizing attitudes toward any child may gradually become an established pattern that is difficult to reverse. It also is *often* difficult to convince a mother that in so doing she is actually limiting and restricting her child's chances for maximum development.

Parents can rarely allow themselves to consciously reject their child. However a significant number of mothers of retarded children cannot help but harbor unconscious resentment and feelings of rejection toward their handicapped child. In the past, when community services were not available and when these unconscious feelings reached an intolerable level, some mothers would begin to complain about a variety of isolated tangential issues until her husband or an involved agency would be manipulated into forcing her to have the child placed out of the home, a decision which she was unable to initiate independently on a conscious level.

Almost all mothers of handicapped children struggle constantly against varying degrees of guilt. Most of this guilt is based upon the fact that they are disappointed in and cannot love their child as they feel a mother should. In addition they struggle with an existential guilt that somehow they are responsible for their child's deficiencies and suffering. This guilt is handled in a variety of ways. Parents might blame themselves or each other, attributing the congenital handicaps to "bad blood" or an hereditary defect on one side of the family. Needless to say, this attitude may place a permanent barrier to a healthy sexual

relationship between the two parents and further impair the normal pursuit of their own emotional needs.

Other parents may see the child as a punishment for past sins or as a negative aspect of their own personality. Such symbolic meanings of their retarded child tend to further isolate the parents emotionally from their child and thus increase their guilt. The child may also be used negatively in problems of marital adjustment, each parent using the child as an excuse or medium to vent their own grievances toward each other.

The "martyr syndrome" is now a well-recognized pattern. The mother verbally accepts her retarded child and constantly talks about him or her as if welcoming the challenge to demonstrate her capacity for sacrifice and devotion. This defense can assume such proportions that in several reported cases the mother had her normal children adopted out so that she could devote herself exclusively to the needs of her handicapped child.

I personally worked intensively with one mother who had a daughter who was so impaired that she existed slightly above a vegetative state. Yet that mother, who earlier had two healthy sons, insisted that she had a close bond of communication with that daughter and continually sought medical treatments for her very frequent illnesses. She managed to keep her daughter alive for over 30 years despite all medical predictions against this. As I stated in the introduction, we do not know the karmic bond or higher reasons why one child chooses a particular parent and visa-versa.

Nevertheless, based upon all of the above, it is important that weekly group therapy sessions be made available to all parents of "special" children.



## Effect of a Handicapped Child Upon Family Autonomy

Only recently has society shown some willingness to consider alternatives to the isolated residential institution for its atypical or deviant children. The growth, in the past decade, of day care centers, special schools, developmental clinics, workshops and activity programs for the multiple handicapped has eased their burden of care sufficiently to encourage parents to keep their retarded child within the home.

Gradually, overwhelming evidence is being accumulated which shows that even severely retarded children can obtain considerable benefit from remaining in a warm and accepting family environment in contrast to their counterparts who are placed in institutions at any early age. They tend to be more sociable, more acceptable in behavior and appearance, and more independent in self-help skills,

This is especially true of children with Down's Syndrome for which a special section is devoted. [Click here.](#)

However, the family needs help in integrating a handicapped child into the social structure, and unless feelings about the handicapped child are understood, the entire family may become handicapped around his or her care.

Every member of a family with a handicapped child modifies directly or indirectly all of their many interactional patterns within the family. The handicapped child also is capable of modifying the behavioral responses of various of its members toward him. To understand the nature of this influence, we must be able to visualize the family unit as a dynamically functioning system with personally and socially motivated goals and expectations of performance for each member.

Ideally, a healthy family functions as an integrated unit to cope with the anticipated developmental crisis of each child as he or she progresses through a natural cycle from birth to maturity, and each member is

generally defined or treated according to his particular role at each stage of this cycle (i.e., baby, toddler, first grader, college student, etc.). In the process, both parents must engage in much experimentation and make many decisions of a trial-and-error nature with an eye toward future expectations.

Meanwhile they can obtain some feedback as to how well they are succeeding by comparing their child with other children of the same age. All the while the child's progress or lack of it is felt as a continual reflection of credit or blame to the parents.

## REALITY STRESSES

The raising of even a healthy or "normal" child in our present, complex society is an arduous task requiring optimal communication and mutual support between both parents as well as a variety of skills, which often are learned through the process of trial and error. Little wonder that new parents feel very inadequate in their parenting roles. The young mother of a first born retarded child is especially unprepared for her responsibilities. With no previous experience or adequate basis for comparison, she must cope with a variety of roles thrust upon her by necessity and by the expectations of our society.

The early care of the child is left largely in the hands of the mother who is constantly faced with a variety of minor emergencies to which she must respond with some kind of decision. When her child has a slight fever, or has a fall, or cuts his finger should she immediately consult the family physician, or is it safe to wait? Gradually experienced parents learn to develop an optimistic philosophic attitude based upon repeated reassurances by their pediatrician that their child has not suffered a brain concussion, or eaten something poisonous, doesn't have a serious disease, that a poor appetite may be normal, that he will get over his rash in a couple of days, and that his diarrhea is "something which is going around now."

But what of the parent of the severely handicapped child who is highly susceptible to respiratory and ear infections, allergies and digestive problems, frequently whimpers as if in pain, has difficulty chewing and swallowing food, has severe orthopedic problems or congenital heart disease and is subject to a variety of epileptic-type seizures? How are they to interpret a new emergency and where should they take their child for help? Private physicians are ill equipped to handle chronic medical conditions which are outside the usual problems of their practice. Although they can offer the parents support, they realistically

are less optimistic as to the prognosis of the various presenting symptoms. Mothers of retarded children often continue to maintain a hyper-response to every gasp or cry, and many live in constant fear that their child will die while unattended.

Parents are imbued with the awesome responsibility of developing the personalities and instilling a sense of identity in their children by their acceptance or rejection. The "mother-child" bond normally begins at birth. Mothering behavior is now known to be a primarily learned, rather than instinctual, a process elicited by various instructional responses from the baby such as smiling, clinging, sucking, and crying.

However the handicapped child lacks the ability to stimulate his mother's normal maternal responses. On the contrary, his lethargy, irritability, inability to suck properly or swallow food instills anxiety, frustration and even disgust upon the part of the mother who, in turn, communicates her own state of tension and insecurity back upon the child. This pattern may result in a cycle whereby the child gradually becomes less affectionate, more apathetic or negativistic, and lacking in normal motivation for social contact.

Sometimes the mother is confused as to the cause or reason for certain negative behavior. It becomes increasingly more difficult for her to differentiate between the negative behavioral reactions which she is inadvertently developing through her inexperienced handling of her child and those reactions which are common to greater or lesser extent in all children suffering from brain damage at birth such as immaturity, hyperactivity, irritability, poor impulse control, low tolerance for frustration, unpredictable temper tantrums and exaggerated fear reactions.

Even experienced parents often feel their patience becoming especially thin when dealing with adverse behavior in their retarded child such as compulsive head-banging, masturbation, extreme negativism and destructive outbursts, especially when the child has severe deficits in the usual modalities of communication.

With mildly handicapped children, new crises occur in adolescence as the child's growing size, sexual development and increasing awareness that they are "different" makes them progressively more unhappy over their relatively dependent state. they want to share the world of their siblings who are dating or have married and left the home. they tend to escape into a world of fantasy punctuated by violent outbursts of frustration. Their communication with their parents may be totally disrupted by vocal exchanges of resentment and anger. The confused parent often handles her own ambivalence by allowing her child to punish her, thus intensifying her resentment as well as the negative self-image of the child.

Parents are entrusted not only with the care taking responsibility of their children but with the obligation to protect them from harm, including physical, sexual, or emotional abuse from unthinking or unscrupulous elements of the outer community. It is difficult for the parents to judge the extent to which they should restrict the outside activities and social contacts of their handicapped child without further hindering his social development. The mildly retarded child is especially susceptible to ridicule and harassment in the school yard and by his peers in the neighborhood who may tease him or make him the butt of their jokes to enhance their own feelings of superiority. Pathetically a handicapped child may acquiesce willingly, out of a need for attention and acceptance, to playing the buffoon or becoming a dupe or scapegoat for a group of delinquent or pre-delinquent boys. Adolescence is a particularly difficult time for the retarded, not only because of their increased drive toward greater social interaction out of the home, but because of society's tendency to view them as sexually aggressive or potentially dangerous. It is not unusual for the retarded boy or girl at this age to begin running afoul of the law for minor misdemeanors ranging from trespassing or similar inappropriate behavior to drug use or sexually unacceptable conduct, the latter usually instigated by those who should know better but who usually manage to escape without being implicated.

Every parent soon learns how to bandage cuts, apply nose drops, use a thermometer and attend to a number of other minor medical problems common to children. In addition to this the mother of the handicapped child must learn to handle braces and special prostheses, dispense medications according to an often rigid schedule, and carry out special procedures to minimize urinary tract infections, skin ulcers, respiratory distress and other medical problems commonly associated with brain damage and mental retardation.

Parents must guide their children through a variety of developmental crises by offering themselves as a model for identification. In this respect, parents almost compulsively tend to adopt attitudes toward training, especially as regards impatience, acceptance, permissiveness and restrictions that closely parallel those of their own parents. But unless they were raised in a household with a handicapped sibling, the parents of a retarded child find themselves in a strange situation where all of their attitudes, reactions, and patterns of care around toilet training, feeding, etc., must be developed "de novo." Meanwhile the handicapped child tends to adopt the unconscious attitudes toward his handicap that his parents hold: denial, resignation, and disappointment or rejection of themselves.

The proper balance between under-control and over-control is an area in which parents of both healthy and handicapped children have their greatest degree of uncertainty. No child comes into the world with the ability to tolerate frustration, postpone gratification, or to mediate his behavior so as to cope effectively with the outside world. These are the attributes of a healthy ego which are developed as a gradual process from repeated

exposure to graded frustrations. Each challenge that eventuates in mastery increases the child's ability to handle further challenges. However, obstacles that are insurmountable lead only to frustration.

Parents should not try to teach their child to tolerate frustration by purposely frustrating him. This always leads to power struggles with devastating psychological consequences to both sides. (Imagine your spouse refusing you a cigarette to teach you to stop smoking.) Control must come from within.

An exception, of course, is the 'negotiable' frustration, where the child must ask for a cookie or say "please" before receiving it. However, the danger of overdoing this must also be emphasized. There should be sufficient unavoidable frustrations in the course of every normal child's day to adequately challenge his coping abilities without inventing artificial ones, unless they are amenable to easy mastery.

A child who is asked to perform beyond his capacity and then punished for failing will develop severe behavioral problems including temper tantrums, avoidance withdrawal, and eventually, rigid personality characteristics that will tend to make subsequent learning all but impossible.

The other extreme is the child who, because he was sickly at birth, is overprotected and over-sheltered and literally rewarded for just being alive. Such children do not learn to develop behavioral repertoires which can be used to elicit positive responses from their environment. They tend to become fearful and insecure children who shy away from any task and who may react to even moderate social or academic pressure with emotional shattering.

Retarded children are especially prone to being treated at either extreme, often in alternating fashion between over-expectation and boredom. And either extreme may have the same result by either forcing or permitting the child to regress into his own self-stimulating inner world. All discipline should be based upon a prior established positive rapport and mutual trust. However, the

## What can be taught to children to modify their judgmental responses when they see a handicapped child?

The prejudices of children often come from adults. The concerns of adults regarding the physical body of their child, soon becomes a preoccupation of the child. Why does a child react cruelly to another child who is retarded, or lame or weak - only to alleviate their own anxieties by negating any possible identification with the child who bears the handicap.

Cruel behavior then results from a rejection of the whole child in an attempt to reject the affliction which he bears. A child who taunts another because of a spastic gait might have an entirely different attitude toward a bird with a broken wing or a stray dog who is lame. Here he can demonstrate sympathy, without his own sense of intactness being threatened.

What, then, might be a helpful approach to this problem? Children must be helped to separate their self-image from its rigid identification to their bodies. The physical body, they must be taught by their teachers, is only a vehicle for the very special consciousness which resides within.

The body ages, breaks down, and has definite limitations, whereas consciousness never ages, only grows, and is unlimited in its potentiality. Our goals as human beings is to learn to appreciate our gift of consciousness and to enjoy our communication with the consciousness of others on ever increasing levels of awareness. Help your child to realize that as they go through life they will meet many people who are less fortunate than they and this should help them to be more appreciative of what they have. Help your child, through questioning to see beyond the handicap of the child, and to recognize where true values lie: Is he kind? Does he want to be of help to others? Does he appreciate a pet who loves him despite his handicap?