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Title

Families of Physically and Mentally Challenged Children: Attitudes, Issues, and Strategies for Intervention

This workshop is designed to familiarize family physicians, and teachers of family physicians, with the following: 1) their personal attitudes and reactions (as influenced by their own families of origin) toward disabled individuals and their families 2) prevalent issues and dilemmas facing such families, both within the family and in terms of the larger society; 3) strategies and approaches for helping such families resolve some of their inter- and intrafamilial dilemmas. Topics presented will focus on a theoretical examination of the role of the disabled individual (and by extension, the disabled individual's family) in the context of American culture; emotional responses of mother, father, siblings, and extended family to the diagnosis of a disabling condition in the child; communication problems within the family resulting from the child's condition; mother-child enmeshment; child-centered families; difficulties for family members in interfacing with the outside world; and a variety of life cycle considerations. The workshop combines presentation of academic information with an emphasis on experiential small-group and large-group exercises.

## ISSUES & CONCEPTS: WORKING WITH FAMILIES OF MENTALLY AND PHYSICALLY CHALLENGED CHILDREN

Coping: refers to efforts to master conditions of harm, threat, or challenge when routine or automatic responses are not readily available. Coping may be problem-focused, or emotion-focused. It may employ strategies of approach or strategies of avoidance. Coping is interactive with the way the family appraises the nature of the stressor. Coping may eliminate or modify conditions giving rise to problems; may perceptually control the meaning of experience in a manner that neutralizes its problematic character; or may keep emotional consequences of problems within manageable bounds.

### SOCIETAL COPING RESPONSES (including those of some professionals)

Although disability exists on a continuum toward normalcy, in most people's minds it is treated as a dichotomous situation: either one is disabled or one is not disabled.

It is convenient in the mind of society for the child to become the disability (the spread effect); and, by extension, for the family to become identified as well closely or exclusively with the disability.

Within our culture, the disabled often are perceived as abnormal, deviant, threatening; too often, they constitute a disliked, despised class. At times, disability may appear almost unAmerican, because of its connotations of dependency, vulnerability, being one of life's losers.

Most people have intrapsychic organizing schemata which prevent the uncomplicated assimilation of threatening material such as confrontation with disability: 1) I am intact and invulnerable 2) There is a just world 3) My world has meaning and coherence 4) I am in control of my own life. Disability challenges all of these assumptions. One of the easiest responses to alleviate the cognitive and affective dissonance created is to put emotional and physical distance between oneself and the threatening material.

It has been established that not only adults, but children hold negative attitudes toward disability, that these tend to increase with age, and that a hierarchy of preferences for disability also exists, with spasticity and mental retardation evoking most rejection.

Research shows that the disabled person "most liked" is one who is least responsible for the disability (victimization) and most successful at coping (mastery). This profile conforms to strongly held cultural values about the proper "patient role," a role which never should be self-inflicted, but if unavoidable, should be met with courage and fortitude.

Common, unhelpful, reactions of others include the following:

Entrenched denial: of fact, of implications, of feelings.

Quick-fix meaning: You were chosen, this child is a blessing, God is testing you.

Tough It Out realism: Face reality, calm down, things aren't as bad as you think, it's not your fault, it doesn't do any good to worry.

Victimization: pity, rescuing.

As a society, we are geared for dealing with situations which are acute, dramatic, and technologically oriented; we are less well prepared to deal with losses which are incurable, and unfixable. In short, we are ill-prepared to deal with the process of grief. Concomitantly, we are quick to pathologize grief.

The physician-parent relationship is often complicated by the physician's (and the parents') own issues surrounding disability. Physicians may experience "failure" with a chronic, incurable patient as a narcissistic wound, a disappointment of their expectations of being a successful healer.

Theories regarding the discomfort of nondisabled persons in the presence of the disabled: 1) Nondisabled persons are reminded of their own vulnerability 2) An underlying belief exists that handicaps represent punishment for evil behavior 3) The core of people's rejection of the disabled lies in their basic fear of death 4) Nondisabled persons fear the disabled because of a fear of loss of mastery and control.

Effective caregiving: 1) Clarification and control - examine problems forthrightly; provide accurate information 2) Collaboration - share concern without sharing distress 3) Directed relief - encourage expression of pent-up feelings 4) Cooling-off - modify tendencies to emotional extremes; encourage self-esteem and self-confidence; share silence and adopt constructive resignation.

### COPING RESPONSES OF FAMILIES

1. Types of chronic stresses in families of mentally retarded children:
  - stigmatized social interactions
  - prolonged burden of care
  - lack of information
  - inability to complete the grieving process
  - father vs. mother stresses
2. Understanding parental responses to a handicapped child requires acknowledgment that much of their responses is motivated by the grieving process. Parents are mourning shattered dreams, the loss of the perfect child. Initial reactions include shock and denial. However, chronic sorrow, a much maligned and attacked concept, continues in cyclical fashion, and includes emotions of anger, despair, self-blame, denial, anxiety, fear, depression. Parents also have to confront awareness of mortality and the fragility of life. They employ the same mechanisms of avoidance and denial cited above, but these are less successful and less sustainable as the threat is more immediate and omnipresent.
3. Grieving is the process by which one separates from a shattered dream. It is cyclical, although not continuous, because at different developmental stages of life, different dreams are being grieved.
4. The emotions that accompany the grieving process are often viewed as pathological or socially undesirable by society. Yet each of them plays an important functional role in generating a sense of healing and resolution. For example, denial can protect the ego from immediate overwhelming assault. Anxiety often helps mobilize the energy necessary to take action toward change. Fear facilitates the recommitment to attachment, to loving, in spite of vulnerability and the possibility of loss. Anger is a response to the violation of one's sense of universal fairness and justice. Overprotectiveness often stems from a lack of trust: The parent has been betrayed once already, and is not likely to allow that to happen again.

5. The grieving process also includes "healing" elements: 1) Completions - healing, acceptance of loss, resolution 2) Resolution and reformulations - enhanced sense of personal power; change from prior feelings of helplessness and loss of control to feelings of mastery and competency 3) Transcending loss - the individual is not bound by loss, is able to change and grow, has achieved serenity without passivity.
6. Common coping strategies which have a positive impact on parents:
  - positive thinking - importance of humor and hope
  - focusing on others' problems: it could be a lot worse
  - suffering is inherent in life, perhaps part of a larger meaning or purpose
  - moving the problem to the periphery of meaning
  - emphasis on living each day
  - emphasizing child's good qualities, rather than limitations
  - normalization - presentation of child as child, rather than defect
  - sharing the burden with others - use of social support
  - other useful strategies: relaxation, problem-solving, self-praise, self-instruction

Of these, most important seem to be endowing child's condition with meaning and sharing burden among family members and outside people.

7. Impact on the marital relationship: Blame is an easy way to deal with feelings of vulnerability and helplessness. It is also common for the mother to become enmeshed with the affected child, trying to recreate that child in a perfect image, leaving the father to wander aimlessly at the periphery of the family circle.
8. Common issues for fathers: 1) Needing to be the strong support 2) Child as an achievement 3) Escape through work 4) Exacerbation of difficulties in bonding with infant 5) Lack of control over situation.

## UNDERSTANDING FAMILIES OF HANDICAPPED CHILDREN: THREE TRAINING EXERCISES

### Free Association

Have students free associate to words such as disability handicap, and mental retardation. Usually a preponderance of negative words emerges (gimp, cripple, limitations, moron, retard, lame, dependent, different etc.). These provide the basis for a discussion of the essentially pejorative stereotypes with which individuals with disabilities continue to be regarded. Occasionally, positive stereotypes will be presented (special, sweet, chosen by God). These words also can illuminate essentially distancing strategies which are used to distinguish those with disabilities from "normal" people.

### Attitudes Toward Disabled Individuals: Family of Origin Exercise

Students recall attitudes toward disabled individuals from their own families of origin. Presentation of specific incidents is also encouraged. What were messages about disability from the family of origin? Sentence completion: My mother would say "Retarded people are..." In this way students realize that some of their own attitudes, biases, and expectations are part of a familial as well as a cultural context; and that often these attitudes express parental views and fears about not being perfect persons.

### Universality of Loss: A Journey Into One's Own Life

Using standard relaxation techniques, students are asked to focus on a loss in their own life (major or minor, current or distant) as a way of illustrating universal dimensions of the grieving process. Movie theater exercise. In subsequent discussion, focus on process, not content of "movie". Each student develops one word of despair, one word of hope connected with "movie".

## CONTENT THEMES

SIX MONTH CRASH: What happened to the parents around 6 mo?  
(less denial, euphoria fading)  
What changes occurred in their language?  
(introduction of "retarded" into their vocabulary)

COMPARISON TO OTHER CHILDREN: is comparison a natural parental response? What are its dangers? benefits? What is the difference between comparison and competition?  
How do you think Haley's differentness from other children impacts on gatherings of extended family?

IMPACT ON FAMILY: In what ways do you think Haley's having Down Syndrome has affected this family? (more stress, conflicts) What has been the impact on husband/wife? (cycles of getting close, pulling away)

PARENTAL EGO INVESTMENT IN CHILDREN:  
In what ways do children become extensions of parents?  
Why might Haley be an embarrassment to her parents?

IMPACT ON SIBLINGS: What might be some impact on siblings of having a retarded child in the family? What appears to be happening in this family?  
(competition for attention; tearful, less carefree)

RESPONSE OF EXTENDED FAMILY:  
What might have made it so difficult for Steve to tell his parents about Haley?  
What is the parental reaction to the cliches of their own parents regarding Haley?  
What was the reaction of maternal grandfather?  
(resisted diagnosis)  
What was the reaction of maternal grandmother?  
(cliches, didn't treat baby as complete child; denial: not really retarded)

## PROCESS THEMES

HUSBAND/WIFE INTERACTION: What do you observe about the interplay between husband and wife at this point?

PARENT/CHILD INTERACTION: What do you notice about parents' interaction with children at playground?

HUSBAND/WIFE INTERACTION: How would you characterize husband/wife interaction around the issue of his involvement? (she-resentful; he-defensive)

AFFECT:  
When husband talks about "stares," how might he be feeling?

AFFECT: What is mom experiencing at this point? She appears to be in some pain. What is her pain about?

COPING: Steve makes a joke about Haley sitting on her grandparents' laps for the "next thirty years."  
What is he trying to express here?

## CONTENT THEMES

REACTIONS OF OTHERS: What is mom's strong desire? (to be seen as mother and daughter, not retarded daughter)  
How do people react to Haley?  
(uncomfortable, avoid them, idealistic stereotypes; rejecting; trying to find bright side)

## PROCESS THEMES

AMBIVALENCE: In the anecdote about the grocery store, mom remarks, "What did she think I was going to do? Give her back? What might mom be expressing at this point?"

COPING: What is mom telling herself when she says she "shouldn't" think about the future?  
(attempt to exert cognitive control)  
What is mom afraid of?  
(losing control)  
What do you think is the "meaning" of Haley's disability to this family?

## DOCTOR-PATIENT INTERACTION: QUESTIONS FOR DISCUSSION

### CONTENT THEMES

**SUB-STANDARD HUMAN BEING** - What is the father afraid of?  
(child not receiving same treatment, being dismissed as curiosity, syndrome)  
How does the power, the expertise of the physician enter into this equation?  
(father's vulnerability, dependency on physician)

### PHYSICIAN DISCOMFORT:

Doctors used to cures, fixing things - what happens when they cannot?

### DOCTOR-FAMILY INTERACTION:

What are mom's beliefs about how well physicians understand the impact of a handicapped child on family life?  
What are some of the important interactive skills the parents identify to improve doctor/patient communication?  
(importance of listening, asking about feelings: distinction between "Do you understand?" vs "How do you feel?": treating child as normal, but also acknowledging Down Syndrome;  
(What does this mean/)  
What other skills are important?  
What kinds of open-ended questions can be helpful?  
(How can I be helpful? How are you feeling? What's all this been like for you?)  
Do you think most patients feel they have permission to express emotion in the physician's office?  
How did the support group suggestion backfire?

### WHAT IS THE RIGHT QUESTION:

In the belly button episode, what was mom's "question behind the question?"  
("I don't know if I can deal with this")  
What makes her ask it in this oblique way?

### PROCESS THEMES

#### PRESENTATION:

The mom is engaged in image-making when she prepares to see the doctor:  
What image and why?  
Do you think the father might have this fear about himself? Why/why not?  
(treating child as syndrome)

#### DESIRE FOR NORMALCY:

Why does mom want a well baby check?  
(Desire for normalcy)

#### AFFECT:

What is mom's affect at this point?  
(angry, hurt: feels diminished by physician)

#### PROCESS OF INTERACTION:

Dad talks about the "superficiality" of interaction with physicians. What does he mean by this? Why is there this quality to their interactions?  
How might it be changed?

#### AFFECT:

How is mom feeling as she relates the episode with the ENT specialist?  
(hostility, helplessness, hopelessness)  
How might you have handled this situation?

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What are your reactions to this family? Do you like them? Do they make you feel uncomfortable? How would you feel about having them in your practice? What could you do to increase the chances of building a successful relationship with this family?