PARENT-PROFESSIONAL INTERACTIONS

I. DIFFERING WORLDVIEWS AND ROLES
   A. Professionals adopt a clinical perspective
      1. Emphasizes pathology
      2. Blames the victim
         a. Can be guilt-inducing in parents
         b. Judgmental regarding failure to comply or progress
      3. Medicalization of all symptoms
         a. Emphasizes categorization, predictability, treatment, cure
         b. Tends to write off chronic conditions
         c. Makes global assumptions about how degree of impairment effects individual potential
            1. Negative expectations about child performance
            2. Overestimate negative impact of child on family
      4. Parents defined as patients, patient-like expectations
         a. Passive, cooperative, agreeing with expert
         b. Dependent on professional for expertise, guidance
         c. Deviant parents seen as troublemakers
         d. Labelling parents
            1. Helps professionals justify own behavior
            2. "Lazy,", "Disturbed," "Doctor-shopping," "angry," "demanding," "manipulative" all may have nonpathologic interpretations
   B. Parents have a personal perspective
      1. Boundary issues
         a. Family is private, personal, inviolate
         b. Becomes territory of whole range of experts
      2. Requirement of becoming an expert, learn professionals' world - no choice
         a. How tomake phone calls
         b. How to be assertive without being alienating
         c. How to ask for help
         d. How to present information
         e. How to evaluate services
         f. How to review records, medical journals
         g. How to participate in a team conference (if invited)
         h. How to understand complex medical conditions
         i. Learn to administer specific medical technology
   C. Professional and Parent Roles (Parsons)
      1. Achievement/ascription:
         a. professional chooses - either selects or avoids disability
         b. parent assigned, no choice in having child with disabilities
      2. Universalism/particularism:
         a. professional interested in all cases of a particular type; impartiality; overlooks individual differences
         b. parent interested in only one case - their child
      3. Specificity/diffusesness:

a. Professional perspective, child not viewed in social context; unidimensional
b. Parents see child as having variety of social roles (helper, playmate, grandchild, sibling) affected i differentially by disability

4. Neutrality/affectivity:
   a. Professional cautioned to be objective, avoid emotional engagement
   b. Parents expect expression of emotional concern
5. Dominance/anomie (submission):
   a. Professional retains control, information, expertise
   b. Parents feel powerless; fear of disagreement
      1. fear of retribution
      2. desire to please, save face

II. DIFFERING SOCIAL/PSYCHOLOGICAL RESPONSES

A. Professionals do have emotional response to child with disabilities, based on social, cultural, and familial context

1. Bias and stereotyping
   a. Bias in expectations - spread effect
   b. Bias in language
2. Stigmatization, dehumanization, blame
   a. Disabled individual seen as despised, disliked
   b. Parents seen as locus of responsibility
3. Fear, sense of threat, vulnerability, helplessness
   a. To order in the universe, just world
   b. To sense of personal control
   c. To sense of professional control
4. Specific personal, family-of-origin issues

B. Parents may also be dealing with many of these issues

C. Parents also confronting other emotional issues
   1. Initial shock, denial
   2. Anger, depression
   3. Search for meaning

D. Parents and professionals may clash emotionally

III. PROBLEMATIC PROFESSIONAL RESPONSES

A. Blame attribution
   a. Common response, although may not be expressed directly
   b. Restores control to speaker

B. Quick-fix meaning
   a. Child is a blessing; you're a special parent
   b. Attempt to provide meaning where none yet exists

C. Tough-it-out-realism
   a. It's not as bad as you think
   b. Reduces anxiety of speaker
   c. Exerts arbitrary, premature control

D. Victimization/glorification
   a. Disabled and families helpless, dependent - need rescuing; lower expectations
   b. Disabled and families superhuman, heroic
   c. Both are dehumanizing responses

E. Evasiveness, withholding information, hinting, mystification, passing buck to specialist

1. Ostensibly attempt to protect parent
2. Generally protects physician from difficult emotional situation

F. Avoidance
1. Literal avoidance of pt, as in dying patient
2. Unwillingness to touch, or look at except superficially

G. Family systems perspective
1. Enmeshment with family
2. Triangulation with other family members
3. Distancing

IV. POSITIVE MODELS AND RESPONSES

A. Transactional model emphasizes
1. child's strengths as well as weaknesses
2. Individual differences

B. Programs and approaches that are child and family-centered
1. Inclusion of parent as empowered partner, often expert
2. Flexibility and individuation reciprocity, collaboration

C. Role-taking
1. Being able to understand and value parental perspective
2. Importance of empathy for parent point of view

D. Parental activism and advocacy
1. Taking responsibility for outcomes
2. Identifying needs and rights

E. Professional advocacy
1. Advocacy on behalf of patient
2. May supercede other role expectations

F. Interactional suggestions
1. Ask about feelings/not understanding information
2. Ask about meaning
a. How does this family understand what has happened to them
b. Put child's condition in context of family's life
3. Listen for questions behind the question
4. Disclose one's own feelings
5. [illegible] "failure" [illegible]
6. [illegible]

Communication Skills

Physician Responses

I Problematic
A. feelings of fear, vulnerability, threat, helplessness, lack of control
1. disabled seen as despised, disliked 2. two worlds - spread effect
3. compensatory response of cheerleading
a. exclusive focus on "conquering" disability
b. only one of many nec. coping strategies
B. Blame attribution
1. DS - too old; abortion
2. Genetic inheritance - shouldn't have had children
C. Quick-fix meaning
1. Child is a blessing
2. You are a special parent
D. Tough-It-out Realism
1. Calm down, don't worry, not as bad as you think
2. reduce anxiety of speaker
3. exert arbitrary, premature control
E. Victimization / Glorification
1. Helpless, dependent → need rescuing; expect less; infantalize, encourage regression
2. Superhuman - heroic
3. Both dehumanize

II Skillful
A. Ask about feelings / not understanding of info
B. Ask about meaning
1. How does family understand what has happened to them
2. Put child's condition in context of family's life
C. Listen for the questions behind the questions
D. Disclose one's own feelings
E. Address issue of permanency, "failure" of medicine, and possible ways of being helpful to family
1. will reduce some of parents' anger
2. reduce some of physician's helplessness
f. Encourage expression of emotion - don't put up sign

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 essentailly 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 won attitudes, biases, and expectations ae 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".