PERSPECTIVES IN GENETIC COUNSELING

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UNDERSTANDING THE FAMILY DRAMA: GUIDELINES FOR COUNSELING STRATEGIES

Barbara Fairfield

The birth of any child is a dramatic event in the family. The stage is set before the child appears on the scene, and, as the child's life unfolds, it becomes easier to look back and understand the contributions of each player and the setting. But a critical analysis of the setting and players early in the drama can guide the professional in predicting the outcome. That is the challenge for the counselor of the family whose child is born with a genetic disorder—not just to support the family, but to anticipate difficulties and intervene before problems arise.

What information is needed to understand the family setting of the handicapped child? Four areas to be explored are family atmosphere, roles of family members, (family constellation), parental style, and the marital relationship.

Family Atmosphere

How does a family into which the child is born view life? The shared values and attitudes as expressed by the family are all the child knows of life. From this narrow perception he or she draws the conclusions that will shape his own drama. For example, a genetically handicapped child born into an overprotective family atmosphere is likely to be more severely affected by his or her handicap than is that same child born into a family atmosphere of mutual respect. Other categories of disturbed family atmospheres that may add to the burden of a child's disorder include rejective, authoritarian, suffering, inconsistent, suppressive, hopeless, pitying, high-standards, materialistic, disparaging, inharmonious, overorderly, and disorderly (1).

Family Constellation

The unique roles that various family members have already assumed challenge the handicapped child to develop his or her own, unique position with the family. For the counselor, an understanding of the psychological role of each family member (first born, second born, middle child, only child, youngest) can provide valuable insight into the family dynamics (2,3). For example, a second-born handicapped child might be more likely to assume a position of helplessness in a family where the oldest child is a typical, responsible first-born and where the mother or father (or both) was the oldest child and took care of younger brothers and sisters.

Parental Style

How do the parents handle the task of raising children? Is their emphasis more on nurturing than on encouraging independence? Are they firm and secure in their disciplinary approach, or uncertain and cautious? What were their own parental models like and how do the grandparents now view their children's approach to child rearing? Do the parents agree or disagree on how to raise the children? Do they share the task of child rearing, or is it assumed to be the responsibility of one parent? The answers to those questions can suggest the difficulties the family may encounter with the birth of a handicapped child (4). If, for example, the mother is primarily responsible for raising the children, the birth of a handicapped child may consume so much of her energy that the father feels more and more isolated from the family. Identification of such parental strategies by the counselor can guide the counselor in the selection of appropriate therapeutic interventions that will encourage more cooperation within the family.

The Marital Relationship

The level of intimacy between the parents of a handicapped child is predictive of the extent to which the handicap becomes the central focus of the family. Parents who are comfortable enough as separate individuals to risk closeness as a couple are not tempted to focus on the child in order to resolve the conflict between separation and closeness. The question is not just one of how supportive the husband and wife are of one another, but of how intensely they safeguard the marital relationship as an entity separate from the reality of the birth of their child with special needs. Couples who are able to maintain their sexual interaction, leisure interests, community involvements, and communications with family and friends in the face of the tragedy of the birth of their handicapped child will be less vulnerable to manipulation and power plays by that child.

Case History

A six-year-old girl with glycogen storage disease type 1 began to resist the required periodic starch feedings. The child's absolute refusal to ingest the starch ultimately resulted in her hospitalization. Analysis of the family atmosphere, family constellation, parental style, and marital interaction clarifies the dynamics of the problem and suggests a therapeutic approach.

The family atmosphere is one of isolation and insecurity. The family lives in a remote area, the mother has no friends, and the child attends a private school. The father's days are long as he is involved in various efforts to increase the family income; he is minimally successful.

The family constellation of the parents and child is significant. The father is the youngest of six children. His three older brothers have all excelled as professionals, despite their very deprived childhood. This father, therefore, is always trying to prove himself—in response both to the success of his older siblings and to his poor background. The mother is a middle child in a family of seven children. She sees her life as a continual struggle and

the large family as a safe refuge. Their daughter, an only child, has become the focus for the father's hope of success and the mother's safeguard from the world. The child is therefore idolized by the parents, who use her disorder to attain their personal goals of competition (the father) and security (the mother).

This couple's approach to child rearing vascillated between authoritative and pampering. When faced with the child's resistance to the starch feedings, the father would first reason with his daughter, proceed to bargaining, to tearful pleading, and finally to shouting and ordering. Later, feeling guilty about the unpleasant scene, the parents would give in easily on some other issue or otherwise assuage their guilt by doing something special for her. In assessing the family situation, it was difficult to decide who was really in charge—the parents or the child.

The marital relationship was one of mutual dependence. The woman relied on her husband for all social connections and the man demanded total service from his wife. Most of their interaction focused on the child and her disorder. Their daughter accompanied them everywhere, even to evening social engagements.

The pattern thus emerged of a family where the child dominated every aspect of the drama. It seems quite logical that she should eventually seize final control over her parents and thereby over her own life. Analysis of the pattern suggested the following approaches for reorganizing the family structure: refocusing the parents on their marital relationship and on their growth as individuals separate from their daughter; promoting the social development of the child, each parent, the couple, and the family; and disengaging the parents from the power of the child's disorder.

Summary

To intervene effectively with the family of a child born with a genetic disease, it is necessary to take a broad view of the family setting. The more the counselor understands about the family atmosphere, family constellation, parental style, and marital relationship, the more enlightened he or she will be in the choice of effective famiy counseling strategies.

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REFERENCES

1. Dewey E: "Family Atmosphere" In Nikelly A G (ed.): *Techniques for Behavior Change*, Springfield, Charles C. Thomas Publisher, 1971.
2. Dreikurs R: *Children: The Challenge*, New York, Hawthorn Books, Inc., pp. 20-34, 1964.
3. Toman W *Family Constellation* (3rd ed.), New York, Springer Publishing Co., 1976.
4. Yura, M and Zuckerman L: *Raising the Exceptional Child*, New York, Hawthorn Books, Inc., 1979.

A REPORT FROM THE NSGC BOARD OF DIRECTORS

Virginia Corson

The 1982-83 board of directors has continued or initiated a number of activities to further the status of the genetic counseling profession, to provide continuing education, and to increase communication among NSGC members. Following is a brief review of some of the current projects.

- Professional issues: preparation of the second professional status questionnaire; collaboration with the American Board of Medical Genetics to continue efforts to secure reasonable malpractice options; consideration of a "distinguished counselor" award
- Education: organization of the 1984 National Continuing Education Conference, "Strategies in Genetic Counseling: Clinical Investigation Studies," June 17-18, Seattle, WA.; submission of a grant proposal to the March of Dimes Birth Defects Foundation for the 1983 conference; collaboration with the board in preparation of a brief description of the genetic counselor's role
- Membership: modification of the application and review process for applicants
- Social issues: continuation of the genetics services survey; reorganization of committee structure and redefinition of activities
- *Perspectives in Genetic Counseling;* response to comments from the 1982 NSGC business meeting questionnaires; distribution by first class mail; solicitation of new subscribers; encouragement of case reporting
- Continuing education: establishment of an *ad hoc* committee; implementation of NSGC continuing education criteria in our own programs; review of outside programs
- Nominations: preparation of the slate for the 1983-84 board of directors
- Regional activities: organization of regional meetings; communication with members regarding suggestions and programs
- Job hot-line: establishment of telephone network to post job openings; advertisement of service in the *American Journal of Human Genetics*
- Licensure: investigation of possibilities of licensure for genetic counselors
- Legal: establishment of a new relationship with the legal counsel for the NSGC; continued investigations regarding attainment of tax exempt status.

Please contact me or the appropriate board member if you have any suggestions or questions about these activities.

Virginia Corson, President of NSGC, is a genetic counselor at the Prenatal Diagnostic Center, CSMC 1001, The Johns Hopkins Hospital, Baltimore, MD 21205.

MEETINGS

The 11th annual convention of the Down's Syndrome Congress will be held on September 30, October 1 and 2, 1983, at the Marriott Inn, in Providence, Rhode Island. Anyone interested in learning more about Down's syndrome is invited to attend. The program includes a convention for adolescents and adults with Down syndrome to be held in conjunction with the primary session. Issues pertinent to Down syndrome will be discussed in plenary sessions and workshops, with unique opportunities for sharing. For more information please write or call: Down's Syndrome Congress, 1640 West Roosevelt Road, Chicago, IL 60608, phone: (312) 226-0416.

CORRESPONDENCE

To the Editor:

We enjoyed reading about the conference on bereavement and grieving process held by Region II in 1982 (*PGC*, Volume 4, Number 1). We have two additions to recommend for your bibliography: *When Pregnancy Fails*, by S.O. Borg and J. Lasker, Beacon Press, Boston, MA, 1981, and *Surviving Pregnancy Loss*, by R. Friedman and B. Gradstein, Little Brown and Co., Boston, MA, 1982.

We would also like to make counselors aware of a workshop titled "Support for Prenatal Decision," moderated by Pauline Park at the 1983 NSGC education meeting. The workshop is based on experience with the group known as Support for Prenatal Decision, a southern California support group for parents who have chosen to terminate a genetically defective fetus. This group facilitates the normal grieving process through contact with other persons with similar experiences and by providing in-service training to physicians, nurses, clinic staff, and counselors. They have also produced a video cassette and a training manual that are available to professional groups and institutions for professional training. For additional information write: Division of Genetics, Room A-527, Loma Linda University Medical Center, Loma Linda, CA 92350.

Sincerely,

June Peters, MS
Genetic Associate
Division of Genetics
Loma Linda University
Medical Center

Pauline Park, RN
Genetic Nurse Specialist
Inland Counties Development
Disabilities Services

THE SIXTH ANNUAL
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Contact:
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March of Dimes
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New York, NY 10017
(212) 922-1460

POSITIONS AVAILABLE

Genetic Counselor: A position is available for a counselor in the prenatal diagnosis and reproductive counseling center, Harbor-UCLA Medical Center. Candidate must be certified by the American Board of Medical Genetics or be board eligible. Fluency in Spanish is preferable. Salary is dependent upon qualifications. Send resume and/or contact: Division of Medical Genetics, Bldg. E-4, Harbor-UCLA Medical Center, 1124 West Carson Street, Torrance, CA, 90502, Attention: Michael Kaback, MD, (213) 533-3756.

Genetic Associate: The University of Utah Medical Center has one position available for a genetic counseling associate starting August, 1983. Candidates must be certified by the American Board of Medical Genetics or be board eligible. The position is primarily clinical and includes participation in all aspects of a busy clinical genetics service. It also includes a 30% commitment to on-going research projects. Send curriculum vitae to: Bonnie Baty, MS, Department of Pediatrics, University of Utah Medical Center, Salt Lake City, UT 84132, or call (801) 581-8943. An equal opportunity/affirmative action employer.

Send all mailing address changes to:
Ann C.M. Smith, NSGC Membership List,
Genetic Services, The Children's Hospital,
1056 East 19th Avenue, Denver, CO 80218.