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A mental health resource guide for parents of children with special needs

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**A MENTAL HEALTH RESOURCE GUIDE
FOR PARENTS OF CHILDREN WITH SPECIAL NEEDS**

**A Project
Presented to
The Faculty of the Department of Psychology
San Jose State University**

**In Partial Fulfillment
of the Requirements for the Degree
Master of Science**

**By
Christine Moreland
May, 1989**

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**A MENTAL HEALTH RESOURCE GUIDE
FOR PARENTS OF CHILDREN WITH SPECIAL NEEDS**

**BY
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SAN JOSE STATE UNIVERSITY

RESOURCE GUIDE FOR SPECIAL NEEDS CHILDREN

Footnotes

Request for reprints should be sent to Christine Moreland, Department of Psychology, San Jose University, San Jose, California 95192.

ABSTRACT

A MENTAL HEALTH RESOURCE GUIDE FOR PARENTS OF CHILDREN WITH SPECIAL NEEDS

by Christine Moreland

This project addresses those unique issues and challenges that impact the lives of parents who have children with special needs. It describes the various responses or reactions parents may experience including denial, grief, guilt, anger, and acceptance with adjustment. Other issues that may arise such as how a child's special needs may impact the family system (marriage, personal care, time) and financial considerations are also examined. The research on this subject reveals that if these challenges become too stressful, it may overload the family. Potentially, the stress may be harmful to the parent, child, or other family members.

The purpose of the project is to develop a mental health guide for parents of special needs children. At the present time, there is no particular guide book or resource which contains this important information.

A total of 220 questionnaires were mailed, with self-addressed, stamped envelopes. The objective was to identify individuals or agencies in Santa Clara County who could provide counseling services to parents of such children. The return rate of 28% indicates that there are agencies in Santa Clara County that could offer counseling services to parents of special needs children.

A MENTAL HEALTH RESOURCE GUIDE FOR PARENTS OF CHILDREN WITH SPECIAL NEEDS

Due to improvements in advanced medical technology, there is an increase in the number of babies being saved. Some 15 million Americans have congenital impairments, that is, defects that are present prior to, during, or shortly after birth, and some 250,000 infants are born with such defects each year in the United States (March of Dimes Foundation, 1981). Unfortunately, advancements in technology and medical improvements do not provide solutions to all problems, and many of the needs of special children and their parents are not being addressed. Parents with such children experience unique challenges that impact their daily activities. The following paragraphs will briefly describe some of these challenges and factors.

One of the factors is the parent's own feelings regarding the disabled child. Some of those feelings include denial, grief, guilt, anger, acceptance and adjustment. The emotions that are listed do not always proceed in that order. For example, anger could be first or grief and guilt could be experienced together, or all emotions could be experienced at the same time. Additionally, it should be noted that not all of the emotions are necessarily experienced.

DENIAL

The first response or reaction is that of DENIAL. This is not pathological denial. It is mentally healthy and necessary for many people. The psyche is quite wonderful, because it only allows in what can be handled at the specific time. "This cannot be happening to me, to my child, to our family," may be the expression of reaction (Smith, 1984). Parents who react to the medical report that their child has special needs by pulling away from the situation may require time and a place to think. McNamara (1977) called this period "Avoid Reality," where the parent needs time to

digest all the information and the ramifications and to prepare for the future. Some examples of doubts and feelings are: "Will I, as a parent have the ability to meet my child's needs now and in the future?" "What about our shattered expectations?", "Where are the answers to medical questions?" and, "We feel a lack of preparation for parenting a child with special needs."

Parents whose feelings become sealed off in response to acute stress are sometimes mistakenly judged to be cold and uncaring (McCollum, 1981). Such a parent may appear competent enough that their inner needs can readily be overlooked. This is not normal denial however, and is not the common reaction. This detachment, lack of emotional display, and perhaps even a rather intellectual approach to the child's problem may encourage physicians to communicate with the parents as though the parents were professional colleagues rather than parents.

While denial is a normal part of the process of adjustment, it is probably the most difficult stage for the child, especially for the child who is beyond the toddler stage. The child's needs are not being attended to, particularly the need to be accepted by those around him. This can lead to the false conclusion that the parent does not care and that in the parent's eyes, he is the negative image of his handicap and nothing more. In trying to deny the more unpleasant realities of a handicap, the parent may also be doing the child a disservice by failing to help him deal with the condition.

GRIEF.

The second common reaction is GRIEF. A parent grieves because of the loss of certain hopes and dreams for their child. One cannot have the same expectations for a child with mental or physical limitations that one has for a healthy child. Some hopes will need to be modified and some must be given up altogether. There is grief in the beginning of the illness and grief again when the parents are faced with the changing

aspects of the child's condition. It should be noted that many children improve (i.e., they learn to feed themselves, albeit late) (McCollum, 1981).

GUILT.

The third common reaction is GUILT. Often parents feel that they have caused the problems. Sometimes society can help reinforce parental guilt, especially for the mother. Smith (1984), notes that some of the questions often asked are as follows: "Did I do something to cause this?" "Am I being punished for having done this?", and, "Did I take care of myself when I was pregnant?" Smith also reported that the feelings of guilt may be manifested in the spiritual and religious interpretations of blame and punishment such as: "Why has God done this to me?" or "What did I ever do to deserve this?" Webster's dictionary speaks of guilt as an act of having committed a wrong. Three most common reactions are resentment toward the child, the feeling that each parent has failed the other, and the feeling that they have in some way failed the child. (McNamara, 1977). Some parents virtually place themselves on trial, playing the role of accused, prosecuting attorney, judge, and jury (McCollum, 1981). Some parents feel responsible for the illness or expect themselves to keep their children safe. In some cultures (e.g. in parts of the Philippines & Mexico) handicaps are considered a punishment for earlier misdeeds. Parents floundering in guilt can cause themselves unnecessary pain, and can sap the energy of their other children (Thompson, 1986).

ANGER.

The fourth reaction is ANGER. Anger may be directed toward the medical personnel who were involved in providing the information about the child's problem. Family members become targets of angry, harsh, irritable feelings. Thus, the problem can color communication among family members (Smith, 1984). There are occasions

when individuals need to be counseled about the correct way of channeling anger (McCollum, 1981).

ACCEPTANCE AND ADJUSTMENT.

After experiencing and working through the different reactions, some parents come to the stage of ACCEPTANCE AND ADJUSTMENT. Within the larger framework of a stigmatizing society, families must learn to accept and cope with the sorrows and frustrations engendered by the birth of their handicapped children. Not all families are successful (Darling, 1982). Parents were felt to be accepting if they: (1) displayed minimal anxiety in the presence of the child or anxiety toward him, (2) displayed minimal defensiveness about the child's limitations, and (3) neither rejected the child nor fostered overdependence (Zuk, 1959b). The cycle does not always end when the parents reach the stage of acceptance and adjustment. For some parents, the cycle will repeat itself but not in the same order. It will change depending on events and issues that parent and child will experience in the course of their lives.

OTHER CONSIDERATIONS.

Financial worries burden families of children with special needs. Despite the combination of the family's medical insurance and government and private services, the financial pressures may seem overwhelming and unmanageable. There may be extra costs for medical treatments, special equipment, as well as for everyday items that must be adapted in special ways, including: (1) modifications to a home or car to allow it to accommodate a wheelchair, (2) additional cost of necessities such as food, clothing, and shoes that are unique to the special needs of the child, and (3) transportation and overnight housing costs for special facilities especially when a child requires long and frequent hospitalizations. Darling (1982) discussed the following comments by parents of special needs children:

1. "State aid is based on one handicap per family. I wrote to the Governor and said, I have four handicapped kids, but I didn't get any help.....Our kids have a phone. It's essential. Other kids go out and play. We can't afford it but we have it.....We also can't afford the swimming pool, but water's the best therapy.....Where else can they go and swim almost every day in the summer? The city don't have it, so I have it." (p.143)

2. "If they want to go someplace, you've got to take them. I've got a van out there that cost me over \$8,000. Normally, you could buy that van for \$5,500. It cost me \$1,300 for a lift. I had to get the seats cut and reupholstered...It's for the kids. Everything we do is for the kids." (p. 180)

3. "When you have a handicapped child, everything is so expensive. Wheelchairs, crutches...it's such a rip-off...Richie wears out a pair of shoes a month." (p.183)

4. "We're always in debt...We just keep paying Children's Hospital a little bit every month." (p.182)

IMPACT ON FAMILY.

A special needs child in the family will impact the lives of the parents. Some special needs children require medical attention, thus the parents frequently spend less time alone with each other. Several writers (Freeston, 1971; Hare, 1966; Kolin, 1971; Schonell and Watts, 1956; and Walker et al., 1971) have noted cases of marital breakdown following the birth of a special needs child. Walker (1971) reported a case of a mother with a baby who has spina bifida saying the following: "I am too tired after

working with the baby all day. We quarrel. Marriage relations are not what they used to be. I would be terrified of having another baby like this" (p.150).

In other cases, the mother reported that the baby was more difficult than her other children, and she said, "His stimulation depends on my mood. These children live off your energy. He lives through me" (p. 470).

Where the marriage is intact, there is often the tendency for the father to isolate himself from the home and for the mother to isolate herself with the children (Feder, 1978). Fathers who manage to be home as little as possible often express the feeling that they have been rejected by the mother, because she spends so much time with the baby. She has no time or energy left for the rest of the family. It has been noted by professionals in the field that American fathers often become extremely active outside the home after the birth of a child with impairments. They frequently take on extra jobs or duties, ostensibly to provide more money for the family but unconsciously to avoid contact with the disabled child as much as possible (Klaus and Kennell, 1976). This puts the enormous burden of caring for the disabled child, both in the home and in terms of bringing the child from one therapy session to another, on the shoulders of the mother.

In other cases, the opposite occurs. In the face of such problems, the wonder is that so many marriages remain intact and are, in fact, strengthened by the sharing of anxieties about the handicapped child (McMichael, 1971). In a study of 107 families who have children that have a disability of spina bifida, the majority of the parents felt that their marital relationship had not been affected by the birth of this baby. Some thought it had improved. As noted by Walker (1971), one parent reported that "It has brought us much closer together. We try to maintain our family feeling. I couldn't have got through this without my husband" (p.175). In Hare's study (1966), he reported

that in a great majority of cases, and whether the child survived or not, parents said that the event had brought them closer together. Fowle (1968) found no difference in marital integration between parents who had institutionalized their retarded children and those who kept them at home. According to Lansky, Cairns, Hassanein, Wehr, & Lowman 1978; Sabbeth & Leventhal, 1984; and Silbert, Newberger, & Flyer, 1982, there has not been an increased rate of divorce documented in studies of families where there are children with disabilities, although it is admitted that this may not be an adequate indicator of marital adjustment in general (Taft, 1987).

The literature demonstrates that parents individually experience severe impacts associated with a special needs child. Some parents meet the challenges successfully. In other cases, conditions are worsened when social interaction between the couple or between the parents and children heightens the stress or makes the personal problems worse (Gelles and Cornell, 1985).

Awareness of child abuse is growing in today's society. Children with disabilities are not immune to being victimized. These handicapped children put a greater strain on their parents, and some parents respond by lashing out at the source of the strain (Straus, Gelles, and Steinmetz, 1980). When there are inadequate institutions and agencies in the community to support troubled families, then the risk of abuse is further raised (Gelles and Cornell, 1985).

The parents who have children with special needs will have challenges which will definitely impact their lives. If the challenge becomes too stressful, it may overload the family. Potentially the stress may be harmful to the parent, child, or family members. Before the situation becomes an overloading factor, the parent should be able to locate an agency or individual to obtain counseling services. The purpose of this project is to develop a mental health resource guide for parents of special needs children

who live in Santa Clara County, California. Also, the resource guide will be available to local mental health and counseling agencies to distribute to parents that have such children. At the present time, there is no particular guide book or resource that contains this much needed and important information.

Method

Subjects

The questionnaire was sent to 220 individuals, groups, agencies, non-profit agencies, institutions, hospitals, mental health facilities, and schools who provide counseling services in Santa Clara County. Many of these individuals are professionals and have different levels of expertise and knowledge in their field of work (licensed professionals, Ph.D.s, M.F.C.C.s, social workers, clinical psychologists, and peer counselors). These groups were selected from the United Way Resource Guide, and the Santa Clara County telephone directory.

Materials

The two page questionnaire had 19 items that were used to access the type of counseling services offered by the agencies, institutions and individuals (see Appendix A). The parent should be able to identify the service providers who deal with issues regarding their special need child's disability.

Procedure

Research participants received a questionnaire by mail which included a self addressed stamped envelope. The researcher requested that the participants complete the questionnaire and return it to researcher within two week time period.

After the questionnaires had been returned, they were carefully reviewed for information given, especially about expertise on particular disabilities and the staff members' background in dealing with issues affecting either parents or family members

of the special needs child. After review and assessment, the information received was typed and put into booklet form. At the end of the calendar year of 1989, the booklet will be available at the Parents Helping Parents office and will be distributed to local hospitals and libraries.

RESULTS AND DISCUSSION

A total of 220 questionnaires were mailed with self-addressed stamped envelopes and cover letters explaining the objective of the questionnaire. The returned response rate was 28%. A total of 61 questionnaires were returned by the agencies, and one was returned by the post office stating that the agency was not in operation.

The 28% return rate may be due to any or all of the following reasons: (1) it seemed like too much trouble, (2) questionnaires may not have been appropriate to a particular agency, (3) the questionnaire may not have reached the appropriate staff member, or (4) the questionnaire was sent right before the Easter Holiday.

Of the 61 questionnaires returned, these are the following results. Four, or 8%, of the agencies do not provide counseling service, but offer services to the disabled population. Eleven, or 19%, of the agencies do not provide counseling service, and do not offer services to the disabled population. Twelve, or 20%, of the agencies provide counseling services, but have no knowledge of disabilities. Thirty-four, or 56%, of the agencies provide counseling service, and have knowledge of disabilities.

Out of the 28% returned questionnaires from Santa Clara County, these are the results by cities: Campbell (1), Cupertino (1), Gilroy (1), Morgan Hill (1), Los Gatos (1), Mountain View (1), Sunnyvale (3), Santa Clara (4), Stanford (1), San Jose (31), and Palo Alto (7).

The return rate of 28% of the 220 agencies that responded indicates that parents of special needs children have the resources available in Santa Clara County to obtain counseling services to meet their situation. This guide will assist and direct parents of special needs children to the appropriate agencies.

REFERENCES

- Darling, R. B. (1979). Families against society: a study of reactions to children with birth defects. Beverly Hills, CA: Sage Publications, Inc.
- Darling, R. & Darling, J. (1982). Children who are different meeting the challenges of birth defects in society. St. Louis: The C.V. Mosby Company.
- Feber, C. (1978). The handicapped child and his family. New York: New York University Medical Center.
- Fowle, C. M. (1968). The effect of the severely mentally retarded child on the family. American Journal of Mental Deficiency, 73, 468-473.
- Gelles, R. J., & Cornell, C.P. (1985). Intimate Violence in Families. Beverly Hills: Sage Publications.
- Hare, E. H. (1966). Spina bifida cystica and family stress. British Medical Journal, 2, 757-760.
- Klaus, M. H., & Kennell, J. H. (1976). Maternal-Infant Bonding. The C.V. Mosby Company, St.Louis.
- Lansky, S. B., Cairns, N. U., Hassanein, R., Wehr, J., & Lowman, J. T. (1978). Childhood cancer: Parental discord and divorce. Pediatrics, 62, 184-188.
- March of Dimes Foundation (1981). Facts '81. (booklet). White Plains, N.Y.
- McCollum, A. T. (1981). The chronically ill child. New Haven: Yale University Press.
- McMichael, J. (1971). Handicap: a study of physically handicapped children and their families. Pittsburgh: University of Pittsburg Press.
- McNamara, J., & McNamara, B. (1977). The special child handbook. New York: Hawthorn Books, Inc.
- Smith, P. (1984). You are not alone: for parents when they learn that their child has a handicap. National Information Center for Handicapped Children and Youth. St. Louis: The C.V. Mosby Company.
- Straus, M., Gellas, R., & Steinmetz, S. (1980). Behind Closed Doors Violence in the American Family. New York: Anchor Books.
- Taft, L. (1987). Handicapped children and youth- A comprehensive community and clinical approach. New York: Human Sciences Press, Inc.
- Thompson, C. (1986). Raising a handicapped child. New York: William Morrow and Company, Inc.

Walker, J. J., et al. (1971). Spina bifida and their parents. Developmental Medicine Child Neurology, 13, 62-476.

Zuk, G. H. (1959b). Autistic distortions in parents of retarded children. Journal of Counseling Psychology, 23, 171-176.

Appendix A
Questionnaire

1. Name of Agency or Institution _____
Address _____
City, State, Zip _____
Phone _____

2. Name of Director _____

3. List the type(s) of client population of the agency:

A. What percentage of the clientele have disabilities?

B. Please list the types of disabilities that the clientele have, and include percentage of each particular disability.

4. List services provided:

A. What types of counseling services does the agency provide:

B. Is the building wheelchair accessible?

C. Is there a TTY ?

D. Does the staff have knowledge of the use of sign language?

5. List the qualifications the counselors have:

A. Please identify the staff's expertise of a particular disability:

B. Of those individuals listed, please indicate if they have experience in dealing with issues pertaining either to the disabled individual, parents or family members of special needs child?

6. What are the eligibility requirements to participate in the program:

7. Please list any restriction(s) in utilizing services:

8. What type of payment sources are available:

9. Office Hours:

A. Do you offer home visitation?

10. What geographical area does the agency cover ?