THE PILOT PARENT PROGRAM:

HELPING HANDICAPPED CHILDREN THROUGH THEIR PARENTS

By: Frank J. Menolascino, M.D.
and Robert Coleman

The problems of parents who discover that their newborn child is mentally retarded or otherwise handicapped are many and heavy. For many parents, the news that their child is handicapped is extremely upsetting and difficult for them to accept. Often, such parents react in pathological ways--by denial, anger, guilt, or depression--none of which is useful in helping them to make the necessary adjustment to their child's condition. It is in this initial state of shock that many parents have institutionalized their handicapped child, a decision they would probably not have made were they properly counselled in the early days and months of dealing with their child's handicap. Essentially, though, to keep and raise their child effectively, the parents must adjust in two ways: they must accept their child's projected limitations as a fact, and they must begin to discover the ways by which his medical and educational needs can be met. But because parents can seldom make this ideal adjustment by themselves, the method and purpose of counselling parents of handicapped children becomes crucial.

Since the early 1950's, the subject of parental response to a retarded child has been given a fair amount of attention in research and psychiatric journals. Much of these writings, however, reflected the prevailing tendency of psychiatrists to disparage the mentally retarded, and to intellectualize (and see as pathological) the parental confusion and doubt that were a normal by-product of their helplessness and ignorance of what the diagnosis of mental retardation really meant. Beddie and Osmond equated the birth of a handicapped child to a "child loss," that is, the death of the hoped-for normal child; hence, parental grief had to be overcome with "grief work."[1] Solnit and Stark followed suit by calling the parental attitude one of "chronic mourning" for the "object loss" of a normal child.[2] Because the family configurations of parents and retarded child was viewed as "abnormal" in these constructs, the counseling approaches that evolved from these theories invariably placed the parents in the role of psychiatric patient. Parental counseling tended to explore the parents' feelings about their own parents and their child in an effort to dissipate their guilt, as if, once they were guilt-free, their troubles were over! The child himself was largely ignored, for there prevailed a rock-bottom pessimism, an embarassing silence, about his potential for growth. Thus there seemed little to do for the child except perhaps to recommend institutional placement and to make the necessary arrangements.

From the vantage point of 1976, we can easily see the inadequacy and wrongheadedness of these earlier efforts at understanding and counselling parents of children with retardation and other handicaps. As this author has pointed out in an earlier paper, what parents of handicapped children need is not treatment of real or imagined neuroses, but knowledge and support.[3] Parents need to know the dimensions of their child's condition and the parameters of his growth potential. They need to know what medical, educational, and other services are available within their community. And above all, they need understanding and support of their feeling that raising a handicapped child is a hopeful, necessary and worthy task.

Times change. The spread of the theory of normalization and the growth of community based services for the handicapped have made parental acceptance of handicapped children more likely. Doctors are now more apt to be sensitive in informing parents of their child's handicap; they are also more likely to be informed about appropriate services available in the community.[4] Nevertheless, even if the "crisis of discovery" may be less traumatic for parents, they have a continuing need for emotional support and programmatic knowledge if they are to do the best for their handicapped child. Few service systems offer parents this continuing support. Some parents, the victims of a physician's insensitivity and ignorance, may immediately institutionalize their child, or, unaware of services or the baby's needs, may permit the critical early months and years to pass without enrichment, training or therapy being given. There are other pitfalls as well for parents of handicapped children. Parents whose child needs a highly specialized service may remain ignorant of ways of obtaining it. Other parents, feeling the general society's devaluation of the handicapped child, may retreat into a kind of isolation out of shame and guilt. They become negative and rejecting, which the child feels; and even worse, they fail to provide the socialization and informal learning experiences on which depends the child's growing ability to fit into society as a useful, albeit handicapped, citizen. Thus, despite the improvement in services for handicapped persons, the parents are "at risk"; their own mental health and their child's future can depend very largely upon their ability to obtain the knowledge and emotional support which the task of raising a handicapped child can demand.

An ingenious and effective means of helping parents to deal with the continuing problems of raising a handicapped child is the Pilot Parents Program of Omaha, Nebraska. The Pilot Parents are a group of about thirty couples, all of whom are parents of handicapped children, willing to offer their knowledge and emotional support to other parents like themselves. Couples with newborn or newly diagnosed handicapped children who are referred to the group become "piloted" parents, who are visited, educated, and referred to appropriate services by a Pilot Parent. The Pilot Parent's primary purposes are several: 1) to guide the piloted parents through the crisis period of guilt and depression that often follows the diagnosis of handicapping conditions by providing emotional support, 2) to give the parents factual information about their child's handicap, and 3) to inform them about the community programs and services available to help their child. Piloted parents are urged to join the Greater Omaha Association for Retarded Citizens (GOARC), where they will meet other parents of handicapped children and learn more of the aims of the parent movement. They are also likely to broaden the knowledge and integrate the attitude changes fostered by their Pilot Parents.

The success with which Pilot Parents have been able to guide and support parents referred to them is due to a large extent to the program's process of matching parents. Families are matched as closely as possible according to the following criteria: 1) child's level of functioning 2) handicapping condition 3) age of parents 4) age of handicapped child 5) family structure, such as sibling equivalence 6) geographic area of residence 7) marital status of family 8) problem in family adjustment 9) race 10) educational level of parents 11) income level of parents. After a pilot parent has been selected to match the new family, a member of the assignment committee relays information about the new family to the pilot parent, who is expected to contact the new family within 24 hours if possible. The pilot parent will then visit and consult the new family as frequently and for as long a period as seems appropriate to their needs.

When piloted parents seem to have adjusted to their child and are fully informed about the services available for their child, they are often offered the opportunity to become Pilot Parents themselves. Although the criteria for selection are not rigid, it is necessary that a prospective Pilot Parent have made a good personal and family adjustment to their child, have a good general understanding of mental retardation and other handicapping conditions, and have demonstrated an ability to relate to, and help, other parents.

Prospective Pilot Parents participate in six weekly two hour training sessions before they are considered qualified to guide other parents through the difficult crisis period. Trainees view films, listen to lectures and participate in discussions to gain a broad basic knowledge of the causes and effects of physical and mental disabilities. When they graduate to become full-fledged Pilot Parents, they have a broad knowledge of handicapping conditions and available community services, but more important, have the ability to better express the positive attitudes necessary for giving strong guidance to their piloted parents.

After two years, the raison d' etre of Pilot Parents remains informal crisis counseling, but on a larger scale. Since its funding by a Developmental Disabilities Council grant in Sept. 1974, the program has grown in membership from the original twelve couples to about thirty. In the process of this growth, Pilot Parents has broadened its initial committment to mental retardation to include all the developmental disabilities--autism, cerebral palsy, epilepsy, and learning disabilities. Nearly every developmental handicap is now represented among its members, and the program's outreach capability, and its prominence, has consequently increased. A number of physicians in Omaha area now routinely refer a couple with a handicapped child to Pilot Parents, confident that, no matter what the child's developmental handicap, a Pilot Parent with a similarly handicapped child can be matched to the new couple to provide them with knowledge and support based on experience. Since Sept. 1974, Pilot Parents have receive 400 referrals for information and counseling; 300 parents or family units have been piloted.

Although the program's service of crisis guidance and service referral is undeniably effective and necessary, the authors believe that the unintended by-products of the Pilot Parent Program make it an extremely important component of community based program for handicapped individuals. The chief by-product has been a sense of community among its members. The group has regularized a calender of social events, training sessions and learning activities. Now nearly every week offers something for some member--a membership meeting, a picnic, a wine and cheese party, a growth group. The result has been the development of a group solidarity that can be, and has been, channelled into a number of areas in which service programs seldom have the money or the mandate to act: moral support of individuals with particularly difficult problems, monitoring of the quality of service programs, and organized political action. The latter two, program monitoring and political action, are not formal functions of the Parent Pilot Program, but rather a logical development of the interest and involvement of the members. Many of the parents have children being served by the Eastern Nebraska Community office of Retardation (ENCOR); since joining Pilot Parents, they have become more knowledgeable and assertive, more able to judge whether their children are being served effectively. As political advocates, Pilot Parents achieved a high visibility during ENCOR's acrimonious funding crisis in the autumn of 1975. Members of Pilot Parents spoke with the Governor, appeared on television, and were the subjects of several newspaper articles. Although ENCOR's funds were cut, a portion of the funds were restored, at least partly, one may surmise, because of the effective advocacy of the individual Pilot Parents.

Although the Pilot Parents, like much of the advocacy movement on behalf of handicapped persons, is largely middle-class and Caucasian- their membership is changing. Approximately 20 low-income and minority group parents have been piloted in the last year. Of these 5 have become active Pilot Parents, who have held several growth groups and luncheons in order to make contacts with that part of the population, the poor, who are so often unserved by agencies for the handicapped. It is really too early yet to say that Pilot Parents has made significant progress in bringing information and knowledge about developmental handicaps to low income and minority groups. It should be noted, however, that the members of these groups are seldom responsive to official representatives of service systems or governmental agencies. By using methods of word-or-mouth referral and neighborhood contact, Pilot Parents have demonstrated, at least on a small scale, a technique to bring knowledge of prevention and information about services to parents whose handicapped children are largely untouched by our knowledge of prevention and treatment.

The authors have so far stressed two aspects of Pilot Parents Program: its effectiveness in its formal function of crisis guidance and service referral, and the more informal and less structured activities that reflect the members' interest and involvement, that is, political advocacy, program monitoring and outreach activity. One should not, however, overlook the personal and psychological benefits the Pilot Parents themselves and their children derive from the program.

Evident among the members is their release from the feelings of ignorance and helpless detachment that frequently erode the interpersonal relationships of families with handicapped children. Because of their frequent contact with each other and with professionals in the field, Pilot Parents have the confidence of knowing how their child can develop and what programs are appropriate to their child's needs. Consequently, one sees a wide variety of choice of programs among the parents: the children of some are in ENCOR programs; other parents have placed their children in integrated pre-school programs; several parents have chosen Montessori schools.

One sees few groups whose members are so positive about their children's worth as Pilot Parents. Many parents of handicapped children <u>do</u> wish to value their children, but because of their unrealistic expectations and ignorance of the child's developmental patterns, they become frustrated and reject the child. In short, they are not aware of <u>how</u> to value the child. Pilot Parents are told primarily to enjoy their child in the present, to value what he can do without reference to arbitrary time frames of supposedly normal development. Such an approach frees the parent to value the child as a being in his own right, and focusses the parents' vision, not on the child's handicaps, but on his abilities. These attitudes, then, the whole milieu of Pilot Parents activities support. Public advocacy, guidance of new parents, and social activities among concerned friends with similar experiences provide a constant reinforcement of the positive attitudes so necessary to both parents and children.

In an ideal community based service program for handicapped citizens, the psychological needs of their parents would rank high among program priorities. The parents are the primary persons from whom the handicapped person learns. And if his development is to be optimal, he must be loved and valued and taught the fundamental skills that may eventually enable him to become a useful self-sufficient citizen. The training and guidance of parents for this task, though expensive, would nevertheless be very worthwhile.

However, in certain areas of the country one already sees a drawing back from appropriate levels of funding and services to handicapped persons themselves. It is therefore unlikely that there will ever be widespread public services to deal with the problems of parents of handicapped persons, no matter how important are the attitudes and mental health of the parents to their children's development. In that context, the importance of the Pilot Parent Program can be seen more clearly. It is a program that provides voluntarily a vital service, that of guidance and education to new parents of handicapped children. At the same time, Pilot Parents is an informal support system of informed concerned parents whose bonds of friendship are strengthened by their sharing and solving of similar problems in the demanding task of raising handicapped children. Finally, it is an advocacy group whose insistence on positive attitudes toward handicapped persons is probably the best assurance that the handicapped will be served by appropriate programs and more accepting public attitudes.

NOTES

1. Beddie, A., & Osmond, H. Mothers, mongols, and mores. Canadian Medical Association Journal, 1955, 73, 167-70.

2. Solnit, A.J., & Stark, M.H. Mourning and the birth of a defective child. Psychoanalytical Study of Childhood, 1961, 16, 523-527

3. Menolascino, Frank J. Understanding Parents of the Retarded--A Crisis Model for Helping Them Cope More Effectively; in Beyond the Limits, edited by Menolascino, Frank J. & Pearson, Paul H. Seattly: Special Child Publications, 1974.

4. Kelly, N.K. & Menolascino, F.J., Physicians' Awareness and Attitudes Toward the Retarded Parts I & II, Nebraska Medical Journal, 1975, 60 (12) pp 489-492; 1976 61 (1). pp 4-6