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A PROPOSAL FOR A PILOT PARENT PROGRAM

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Overview

In order to expand those programs of the Greater Omaha Association for Retarded Children (GOARC) which provide assistance and information to parents of retarded children, we propose a "pilot parent" program in which experienced parents of mentally retarded children would be matched with parents of newborn, newly identified, and recently acknowledged retarded children, so that various forms of support could be provided to these "new" parents. Because of the lack of information on the part of most parents regarding mental retardation, and the trauma that may occur when a parent discovers his child is retarded, this program could be extremely important and beneficial for the child and the family.

The program would rely on a group of parents of retarded children who have demonstrated an understanding of mental retardation, who have made an exemplary adjustment themselves, and who appear to have the capacity and willingness to help other parents. It would be the mission of these established parents to help the new parents in as many ways as possible, such as the following: 1) providing emotional support by serving as someone who has "already been there" to whom new parents can talk; 2) furnishing general facts and information, including brochures or books, regarding mental retardation; and 3) transmitting specific information regarding the parent movement, professional services, and programs available. Professional practitioners in various areas, such as pediatrics, dentistry, optometry, etc., might be recommended, and information provided about available developmental centers, residential services, or family assistance.

The pilot parent service is a logical extension of existing GOARC programs, and would assume that pilot parents had undergone orientation and leadership training, such as those provided by the GOARC Family Education Committee and the Mental Retardation Manpower Development Station at the Nebraska Psychiatric Institute. The task of pilot parents would be much like ^{that} of special-interest discussion group leaders, but the exchange would take place on a one-to-one or family-to-family basis.

In the same way in which special interest groups are formed, new parents would be matched to pilot parents as closely as possible. Such matching could be on the basis of the mentally retarded child's functional level, cause of retardation, secondary handicap, and possibly even family structure. For example, a new family with two older children and a new-born retarded child might be matched with a slightly older pilot parent family of the same structure, but with a slightly older mentally retarded child. In this way, problems with siblings could be discussed between parents, and these siblings might eventually be matched for beneficial interaction with each other. Pilot parents might also include a family where parents were initially non-understanding, but where they later learned to accept their child's abilities realistically, thus being able to relate to new parents with similar feelings.

In addition to being of benefit to new parents, the pilot parent program probably would also serve two important secondary functions: The expansion of GOARC membership and the generating of much-needed leadership within the parent movement. Thus the new parents might be induced to join GOARC and become active in it. Indeed, they might eventually become pilot parents themselves. Furthermore, the matching of pilot parents to new parents

might also serve as a way to form new special-interest discussion groups for small groups of parents. When the initial problems have been dealt with, or when the continuation of one-to-one exchange no longer seems needed, a pilot parent might become the leader of a discussion group which might include some or all of the new parents he has worked with. Finally, undergoing training to become a pilot parent, and functioning as one for sometime, constitutes excellent preparation for other leadership roles within the parent movement.

To summarize, the pilot parent program fits neatly into the family education program of GOARC in that it would provide a new form of support for parents, take advantage of existing programs, and could result in the formation of new special-interest groups and parent leaders. In fact, there are not many programs that yield such a unique combination of benefits.

Description of Program

The proposed pilot parent program will be described in more detail regarding the following aspects: Screening and selection, training, referral sources, matching, staff support, and funding. Some of the more technical aspects of implementing the program, will be discussed the section thereafter.

Recruitment

The recruitment of pilot parents will be accomplished by a number of techniques, which will change as the program evolves. This will be outlined in more detail in the next section, Details of Implementations.

Recruitment and ~~selection~~ of pilot parents will be very selective, ^{initially} In other words, no mass recruitment will be undertaken at first. Instead, the GOARC Director of Community Services would attempt to recruit only parents whose qualifications appear exceedingly high.

The determination of whom to recruit would be made jointly by the GOARC Director of Community Services, and the Pilot Parent Subcommittee of the GOARC Family Education Committee. The GOARC Director of Community Services may be requested to obtain suggestions as to potential candidates from the GOARC Board of Directors, the Chairman of Parent Program Groups, leaders of special-interest discussion groups, other leaders in GOARC, and staff members of the Eastern Nebraska Community Office of Retardation (ENCOR). After deciding whom to recruit, the Director of Community Services would approach the families individually, explain the program, and try to interest them in applying to become pilot parents.

After the program has been operational for sometime, the original pilot parents may want to nominate other parents. Later on, appeals may be made through the GOARC Gazette (Newsletter of the ARC) and GOARC meetings for parents to apply to become pilot parents.

Screening and Selection of Pilot Parents

The GOARC Director of Community Services would interview and take applications for all parents who wish to apply as pilot parents (a sample application is appended). All applications would then be reviewed jointly by the Director of Community Services, and by the Pilot Parent Sub-Committee of the Family Education Committee.

Pilot parents would be approved on the following criteria:

1. Good personal and family adjustment.
2. General understanding of mental retardation.
3. Identification with and active membership in GOARC.
4. Demonstrated ability to relate to and help other parents (most likely judged by observations in various GOARC activities, particularly Family Education activities).
5. Moral standing in the community.

Training

Prior to any involvement in pilot parent activities, all pilot parents would take part in basic orientation classes provided by the GOARC Family Education Committee, or the Mental Retardation Manpower Development Station at the Nebraska Psychaitric Institute.

In order to give parents a good general background in mental retardation and appropriate ideology, basic orientation should include, but not be limited to, the following areas:

1. Introduction to mental retardation; definitions, causes, prevention, ect.
2. History of management of the mentally retarded.
3. Philosophy, normalization, acceptance of differneces, integration, dispersal, dignity of risk, and rights of the mentally retarded.
4. State and County plans.
5. Local services available in our area.
6. Strong ARC orientation.

In addition to the general orientation, it is felt that pilot parents will also need a few sessions of specific training in working with other parents. Hopefully, the entire orientation and training of pilot parents could be accomplished in a six-month period of time.

Referral Sources

Initially, the major sources of referrals for new parents would be from the GOARC and the ENCOR Public Inquiry Services. The number of new parents who contact these two agencies now is sufficient to justify a pilot parent program. Given the great lack in services for new parents, it is assumed that parents, who take the initiative to call these agencies would be interested in receiving the services of a pilot parent program.

As the pilot parent became established and proved its value, a public information campaign would be initiated so that other agencies and professionals who come in contact with new parents, would be aware of the program, and refer additional parents. Very specific efforts should be made to obtain the cooperation of family counselors, social workers, ministers, nurses, physicians, psychologists, teachers, and public health officials.

Matching

Both pilot parents and new parents interested in the program would be asked to provide similar information about themselves. This information could then be used for matching pilot parents to new parents. The form for new parents (as appended) would be completed by a staff member of GOARC, or possibly a volunteer, but would not be completed by the new parents themselves.

The matching process could become more refined as the program expands, and as the number of pilot parents increases. Therefore, the criteria for matching, listed below are in the order of perceived importance.

1. Functional level of the retarded child.
2. Race.
3. Cause of retardation and/or secondary handicaps.
4. Age of parents.
5. Age of retarded child.
6. Educational level of parents.
7. Geographic area of residence.
8. Income level of the family.
9. Marital status of the parent.
10. Family structure, such as sibling equivalence.
11. Problems in family adjustment.

The actual matching process could be accomplished by the Director of Community Services, And/or the Pilot Parent Subcommittee.

Staff Support

The Director of Community Services would provide various types of support to the pilot parents. Among these might be brochures or written materials on mental retardation in general, GOARC, the pilot parent program, bibliographies on various topics, etc. Brochures could be given not only to new parents, but also to professionals who are potential sources of referrals. The professionals would be asked to either give the brochures to new parents, or to display them in their offices. The written materials might also include sets of guidelines to the pilot parents (such as the one appended to this paper), complete and up-to-date listings of community services, so that new parents could be advised as to which agencies or persons to contact who can provide the services needed by their child. The list could include a description of ENCOR, other services, and the person to contact in each agency. In order to refer new parents to appropriate dentists, pediatricians, ect., who are particularly interested in and competent in working with the mentally retarded, the pilot parent need also to have access to a file, developed by GOARC, of professionals in such specialized areas.

Another form of support furnished by the Director of Community Services would be the provision ^{of} on-going guidance, support, and advice to pilot parents regarding specific problems or questions which may develop. Consultation with specialists (such as attorney, a psychiatrist, etc.), may be developed in the later phases of the program. More technical problems could be referred to such consultants.

Periodically, the pilot parents would meet together with the Pilot Parent Subcommittee and Director of Community Services. In this way, pilot parents could exchange ideas, and discuss mutual problems. Also, these meetings would serve as a means for the staff member and the committee to keep informed of the problems and progress of this program.

The pilot parents will be provided with forms on which to jot down the dates on which they have contact with new parents, and a few comments about each contact. The Director of Community Services will be responsible for keeping these records, as well as records regarding assignments, visits, problems, terminations, and evaluations of results. Also after the end of the one-to-one relationship with their pilot parents, the new parents will be interviewed by the staff member, in order to evaluate the effectiveness of the program. Some new parents may then be asked to serve as (a) advisors to the periodic pilot parent meetings, (b) speakers in seminars for professionals, (c) consultants to those planning the training for pilot parents. They may also be encouraged to consider preparing to become pilot parents themselves when they have become better established in their role.

Another important aspect of the staff's role is to serve as a liaison with other agencies, and to generate publicity about the program. It will be the responsibility of the staff member to work with the public media to obtain TV and newspaper coverage of this service. The staff will also arrange seminars for the professionals from whom we would expect to receive referrals of new parents.

A summary of staff responsibility is provided in appendix. One of the reasons for colating, repeating, or further specifying the responsibilities of the Community Services Director is that this summary could be used in drafting a job description for such a staff position, recognizing of course that such a staff member would have many additional duties.