PILOT PARENTS • PROGRAM •®

A DESIGN FOR DEVELOPING A PROGRAM FOR PARENTS OF HANDICAPPED CHILDREN

By
Fran Porter

Edited By
Robert Coleman

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A Program Sponsored By The Greater Omaha Association for Retarded Citizens
3212 Dodge, Omaha, Nebraska 68131

The Pilot Parent Program is sponsored by the
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FOREWORD

Many parents of handicapped children help each other, share experiences, joys, frustrations and provide invaluable support to each other. There is a common bond between parents who have handicapped children. Yet many times parents are isolated from meeting other parents for years after they first receive the diagnosis that their child is handicapped. How much better it is when this meeting takes place right away!

This manual is written for people interested in developing a Pilot Parent Program. The uniqueness of the Program is that it provides a systematic approach designed to enable parents to reach out and be available to talk with other parents as soon as they learn that their child is handicapped. Parents who receive help at this time of emotional crisis tend to make an earlier adjustment to the reality of having a child with a handicap and an earlier acceptance of the child as a valuable individual.

The author of this manual is an expert, who, based on her own experience as the parent of a mentally retarded child, had a dream that other parents would not have to face the same experiences she had. Fran Porter's ideas, her insistence that our ARC provide more meaningful and earlier help to new parents, and her relentless work led to the establishment of the Pilot Parent Program of the Greater Omaha Association for Retarded Citizens (GOARC).

From the beginning, the Pilot Parent Program was supported by professionals in GOARC. Dr. Wolf Wolfensberger, psychologist, was most instrumental in working with Fran and me in the development of the concepts and the design of the Program. From my own experiences as a caseworker, I was committed to the Program. Many other professionals from various fields have also contributed their support to this parent-centered, parent-operated Program.

How would I hope my fellow professionals would see this development? As an adjunct. As the provision of something that they cannot provide — the understanding and knowledge that comes from raising a handicapped child. Pilot parents are not professionals and do not replace the need for professionals' involvement with families. But working together, pilot parents and professionals can be a powerful force in improving the lives of handicapped citizens, and the lives of those who enable them to grow and learn, their parents.

Shirley Dean
Co-Founder and Co-Chairman of
the Pilot Parent Program
October, 1978

AUTHOR'S PREFACE

As the parent of a mentally retarded child, I know from my own experience the need for a Pilot Parent Program.

Our son Dana was born in November, 1961. Even though we suspected "something was wrong" before we took him home from the hospital, it took two years of waiting, wondering, questioning, and agonizing before we were finally informed by a doctor that he had Down's Syndrome.

For the next two years we lived with the fears and frustrations one must endure when facing the unknown. One's whole life becomes unknown, insecure because there were too many questions we couldn't begin to answer: Would Dana grow and develop? Would he ever go to school? Could he ever hold a job? And most of all, that mysterious label stuck to him like a middle name — Down's Syndrome. What, we kept asking ourselves, is Down's Syndrome?

It is the torment of these questions that isolates the parent of the handicapped child. We felt isolated because we were certain that no one- not neighbors, not relatives, not friends—could really understand, could empathize, with our feelings of anguish and helplessness. The fear and uncertainty of not knowing what, if anything, we could do to help Dana became the center of our lives.

In the summer of 1965, when Dana was nearly four, we finally met other parents of children with Down's Syndrome. They not only answered our questions but told us of special services available for our son. For us, it was the moment when our isolation ended, when we found that there were others who could understand the doubt and worry and frustration we felt for our son. For our family it was a new beginning: there were services available for Dana; for my husband and me, for the first time, there was hope.

We began to adjust finally to having a handicapped child in the family. We joined the Greater Omaha Association for Retarded Citizens. We learned all that we could about mental retardation. After a time I began to see how much it had meant to me to meet other parents of handicapped children. They had brought our family and me out of that disastrous state of frustration and hopelessness that can destroy a family. They told us of ways to help our son. But most of all, they showed us that having a handicapped child is not the end, but a challenge to begin.

From that realization came this idea: to help other "new parents" by making it possible for them to contact experienced parents of handicapped children as soon as they were informed that their child was handicapped. In the fall of 1970, with the help of co-founder Shirley Dean, the aid of the Board of Directors of the Greater Omaha Association for Retarded Citizens, who sponsored the program, and the dedication of many parents of handicapped children, the Pilot Parent Program was formed.

Fran Porter October, 1978

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PART I

THE PILOT PARENT PROGRAM

The Pilot Parent Program is one in which parents of handicapped children help other parents who have recently learned that their child has mental retardation, cerebral palsy, epilepsy, or autism. The Program's main purpose is to provide supportive experienced parents to pilot "new parents"* through the initial difficulties of accepting that their child is handicapped, learning about that handicap, and finding the proper services to aid their child in his or her development.

For most parents of handicapped children, that initial period is indeed an emotional crisis. Both parents feel guilty, angry with each other, depressed, unable to explain why one of life's happiest events has apparently been irreparably spoiled. Mothers of children born handicapped frequently speak of a period of unshakeable gloom and self-pity, in which it was a great effort for them to care for their children. Fathers, always excluded somewhat from the interaction of mother and child in infancy, edge farther away, unable to talk about the child they are not sure they can accept. Relatives, who are usually so helpful at the time of childbirth, don't call because they don't quite know what to say. The result, frequently, is that the parents are left alone, caught in a vicious circle of anger, depression, and disbelief. One couple, now pilot parents, described their family, in that early period, as "an island with no contact with the outside world."

Parents who experience this "crisis of acceptance" can be helped in a unique way by parents who have overcome the difficulty of accepting the fact that their child is handicapped. The experienced parents offer something that other support systems--friends, clergymen, physicians--cannot provide: the fact that they are intimately familiar with the

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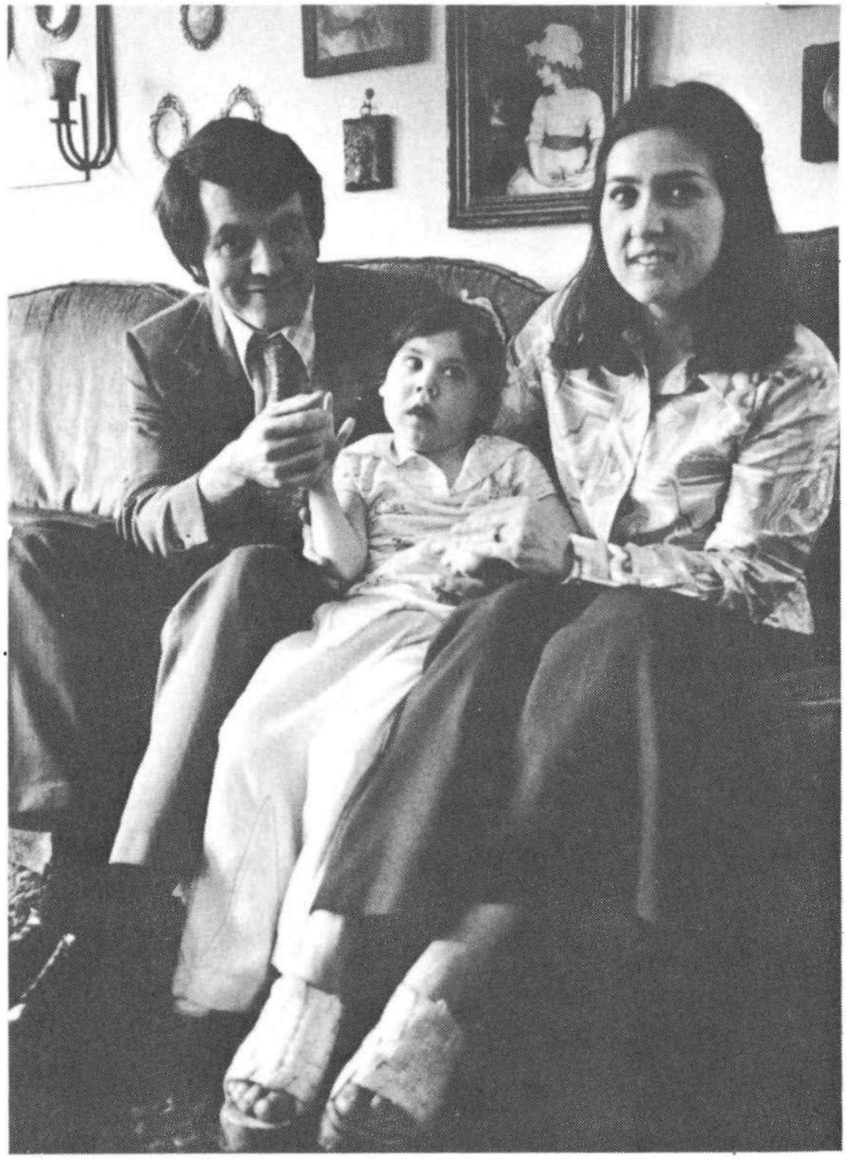
*There appears to be no brief phrase that adequately describes those parents who are referred to Pilot Parents because their child is newly diagnosed or identified as handicapped. For the purpose of this manual and the Pilot Parent Program they are termed "new parents" and will be termed such, without quotation, throughout this manual.

emotions and real problems that having a handicapped child presents to the new and often bewildered parents.



Pilot parents are themselves parents who have learned to accept their handicapped children. As pilot parents, they have no magic answers to impart to troubled new parents. What they do impart, however, is acceptance and a willingness to talk about the problems and pleasures of raising a handicapped child. They convey as well positive attitudes toward their own child, who usually has a developmental disability similar to the child of the new parents. Ordinarily, pilot parents are matched to new families by the similarity of the handicaps, as well as similarities in background; a new family with an epileptic child, for example, will usually have a pilot parent whose own child has epilepsy. Thus the pilot parent can be a source of information to the new family about the particular handicap, and about the location of appropriate services for the child.

New parents can be referred to the Pilot Parent Program through a number of sources, and, as the Program grows and becomes better known, the sources become more varied. Family physicians, obstetricians, and nurses in obstetrics and pediatric hospital wards frequently alert parents of newborn handicapped children to the existence of Pilot Parents. Social service agencies, too, refer families to the Program, as do new parents themselves, who are often highly enthusiastic supporters of the Pilot Parent Program.

The Pilot Parent Program contacts a new family only when the assignments committee chairperson learns that the family is interested in talking with a pilot parent. The Program does not solicit new parents, nor is it forced on an unwilling family.

When the chairperson learns by referral or a call from a new family that they would like to talk to a pilot parent, he or she initiates a three stage process:

1. the chairperson gathers general and family background information from the new family in order to match, as closely as possible, that of the pilot parents who will visit them;

2. the chairperson selects an appropriate pilot parent, who is urged to make the initial telephone contact within twenty-four hours;

3. when the pilot parent visits the new family for the first time, he or she gives the new family pamphlets, brochures and booklets that pertain to the child's handicap. These are brief and easy to read and satisfy one of the new family's most urgent needs, information about their child's handicap, possible medical needs, and his needs for special services.

After the initial meeting takes place, the relationships between the pilot parents and the new parents will develop in a direction largely set by the needs of the new parents. Occasionally a new family will want or need no more than the initial meeting. Ordinarily, though, the relationship develops through frequent contacts spurred by the insistent questions of the new parents, a good sign that they are trying to deal with the child's real present and future needs. The pilot parents assist the new parents through this crisis period by frequent contacts, answering these questions, and encouraging them to participate in social activities. Most of all, though, they assist by being patient and available friends who will listen and who will share their experiences in coping with the same feelings and frustrations.

What new families gain from the pilot parents is not so much answers as much as attitudes and expectations. New parents of handicapped children are apt to view their child's handicap as a catastrophe, a permanent blight on their family's future. In their pilot parents, however, they see people who have raised a child with a similar handicap, and who take pride and feel joy in their child's achievements. Pilot parents demonstrate a particular kind of courage that new parents want and need to see: the courage to accept the child as he is, the courage to put away doubts and fears and to raise the child with love. Finally, new parents have an opportunity to meet the pilot parents' handicapped child, who is frequently an older child with the same handicapping condition as the child of the new parents. For many new parents, this opportunity marks a decisive moment of attitude change.

One parent, recalling her meeting with her pilot parents' son Kevin, felt an immediate change in her perspective of her son Chris:

> "Just seeing Kevin, who, like Chris, has Down's Syndrome, was an overwhelming experience for me. My whole view of Chris had been negative, but seeing Kevin talk, run, and look at books, my whole outlook on Chris became positive. Suddenly I became aware of what Chris <u>could</u> do, and that shift in our attitude made all the difference for us."

The Pilot Parent Program has many ways to assist new parents. In addition to facilitating the relationship with their pilot parents, the Program encourages new parents to attend morning coffees, films on various handicaps including that of their own child, and growth groups.

These activities not only offer the new parents the opportunity to learn more about their child's handicap, but also introduces them to other families whose experiences may be similar to theirs. Many strong friendships have developed out of the many social activities of the Pilot Parent Program.

As new parents become more sure of themselves, they no longer require the strong support necessary at the beginning. The pilot parents gradually ease away, leaving the new parents on their own. By this time—and it might be six weeks, three months or one year--the new parents have gained knowledge and understanding of their child's handicap, have made arrangements for appropriate community services, and are able to face the future in a positive way.

The pilot parents themselves must first qualify for the program, and then undergo 18 hours of training. They must learn the principle of normalization: that a handicapped person will learn and develop in optimal fashion if he is treated normally and is included in those activities appropriate to his age group. Pilot parents must understand generally the developmental disabilities, as well as the range of community services for handicapped persons available in the community.

Pilot parenting can be time-consuming and therefore parents are asked to make only a one-year commitment. However, it is not compulsory to leave at the end of the year, and very few do. During this year, pilot parents attend monthly meetings for the purpose of keeping abreast of new developments in research, new programs in the community, and sharing experiences with one another.

Pilot parenting can be very demanding. However, the inner satisfaction and the benefits the pilot parents receive from their association with the new parents is well worth the time and effort. Not only do the parents grow from the association with the program, but the pilot parents grow as well. One parent summed up her experience in the Pilot Parent Program in these words: "I think every parent of a handicapped child ought to have that kind of opportunity--to help other people raise their child better, and to enrich ourselves from knowing people with experiences and feelings similar to our own. And in the Pilot Parent Program, that is what we do..."

THE PHILOSOPHY OF THE PILOT PARENT PROGRAM

The Pilot Parent Program is based on the philosophy that parents of developmentally disabled children experiencing crises can be helped by parents who have made an exemplary adjustment to their own handicapped child, and who have the capacity and willingness to help others by sharing their experiences. These parents share, too, their belief that every child is a valuable and developing person, who is entitled to develop to his fullest potential in the mode of services that is least restrictive in accordance with his individual needs.

Further, it is the philosophy of Pilot Parents to share their knowledge with new parents so that no child will be institutionalized due to lack of awareness of services in the community.

In addition, the developmental growth of parents participating as pilot parents will produce a metamorphosis of attitudes, values, capabilities, concerns, and involvement creating a common bond that draws closer the parents, their families, and the community.

ESTABLISHING A PROGRAM

A Pilot Parent Program may be established by any number of people, anywhere. A parent of a handicapped child, realizing the need for such a program in his community may advocate for its development. The staff member of a service agency, aware of the value of the program to parents of handicapped children, may advocate among parents to organize a program. Or perhaps a group of parents may band together to establish a program.

Before actually recruiting parents to train to be pilot parents much groundwork must be done. Some of the necessary steps in this preparation include the following imperatives:

- Read all materials available concerning the Pilot Parent Program to ascertain whether or not such a program is suitable for their community.

- Poll other parents of handicapped children to determine whether or not they also feel there is a need for the program: Would they participate? Would they give time and energy to it? In what capacity?

- Acquire a sponsoring agency, if possible; consider an Association for Retarded Citizens, or the Epilepsy, Cerebral Palsy, or Autism Associations. Such an agency, because of its visibility to the public, its contact persons, and its knowledge of funding and publicity, can be extremely helpful to a fledgling Pilot Parent group.

- Inform local leaders in the community, professionals, and interested citizens about the program and ask them to participate in its development.

- Establish a steering committee of parent leaders and community persons to plan the development of the program.

Starting a Pilot Parent Program that is successful, visible, and meets the needs of parents of handicapped children can seem like a huge task. It did to the founders of Omaha's Pilot Parent Program. Nevertheless, the need that parents feel for such a program gives great impetus to establishing it. The first step, and the hardest, is to decide. The steps outlined above, which follow that decision, are much easier.

THE STEERING COMMITTEE

To establish a Pilot Parent Program in your community it is desirable to have a steering committee to assist in its development, rather than one person attempting to accomplish the task alone. It is essential that the majority of this committee be volunteer parents who assume responsibilities in areas such as the following:

1. chairperson
2. publicity
3. assignments
4. social events
5. secretary
6. educational materials.

The roles of the steering committee members are as follows:

Chairperson:

1. Conduct all meetings.
2. Arrange for speakers for training sessions.
3. Arrange for meeting rooms.
4. Liaison between sponsoring agency and committee.
5. Obtain names of, and contact, prospective pilot parents.
6. Maintain records regarding operation of the program.

Publicity:

1. Arrange for all publicity for the program.
2. Contact radio and television stations.
3. Contact newspapers, local and organizational newsletters.
4. Arrange for parents to participate in all publicity.
5. Maintain records of all publicity used, media contact persons, etc.

Assignments:

1. Receive all referrals.
2. Match, select and contact pilot parent regarding referral.
3. Assist pilot parent with referral if necessary.
4. Maintain detailed records of referrals, assignments, and follow-up.

Social Events:

1. With assistance from other pilot parents, arrange all social events involving the pilot parents and those for pilot parents and new parents, coffees, picnics, parties, etc.
2. Maintain records of events, contributing organizations, costs, donors, etc.

Secretary:

1. Record minutes of all meetings.
2. Mail minutes to steering committee and pilot parents.
3. Answer correspondence.
4. Maintain minutes of meetings, correspondence, etc.

Educational Materials:

1. Review and select all reading materials, films, etc., used by the Pilot Parent Program.
2. Maintain records of materials reviewed and used.

In some communities, the committee may consist of only two or three parents. In such cases each person would take charge of several areas of responsibility. Naturally the more persons on the committee the more can be accomplished, if the roles and responsibilities of each member are sufficiently clear.

The steering committee, as a whole, plans the training program, assisted by the additional members of the steering committee, who may be professionals in the field, or perhaps interested citizens. Professionals, such as doctors, ministers, social service representatives, parent group liaison person, etc., may offer valuable assistance in the development of the training for pilot parents and in the design of the Program. They may also be a major source of referrals to the Program. Interested citizens may be a valuable source of information for the publicity campaign carried on by the committee. They, too, can contribute to the Program's overall development.

A more efficient program can be developed if parents and professionals work together as equals, with one goal in mind: to assist the parents of a newly identified handicapped child during a most critical time in their lives.

Problems can arise in a Pilot Parent Program. These may be personality conflicts, philosophical disagreements with the sponsoring agency, disagreements with consultants to the Program, differences between parents who did and those who did not receive early services for their children, or conflicts between agencies that seek to use the Pilot Parent Program as an ally. To assist other Pilot Parent Program steering committees in resolving these potential problems. The following list of principles is included. These principles have been a very useful guide for the resolution of conflicts in the Omaha Pilot Parent Program.

PRINCIPLES FOR THE OPERATION OF PILOT PARENT PROGRAMS

1. The common welfare of all the families of handicapped children should come first.

2. Personal growth of each pilot parent depends on unity.

3. The Pilot Parent Program is operated with a group purpose. There is no authority other than the group as it expresses itself. Our leaders are trusted servants; they do not govern.

4. The only requirement for the services of Pilot Parents is a desire to be helped with the acceptance of one's handicapped child.

5. Each group should be autonomous, except in matters affecting the Pilot Parent Program as a whole.

6. Each group has one primary purpose--to assist other families with handicapped children.

7. Every group of pilot parents must be fully self-supporting.

8. Where needed, programs may have a staff person; the pilot parents must remain non-professional.

9. The Pilot Parent Program may create steering or advisory committees directly responsible to the pilot parents, piloted parents, and the sponsoring agent.

10. The Pilot Parent Program shall refrain from expressing an opinion on outside issues. Thus, the name of the Pilot Parent Program will not be drawn into public controversy.

11. The Pilot Parent Program has a philosophical foundation, ever reminding us to place principles before personalities.

RECRUITING PARENTS

Selecting parents is probably the most important step in building a successful program. Being the parent of a handicapped child alone, does not, by itself, qualify a person to be a pilot parent. It is, however, a prerequisite.

Names of parents of handicapped children may be obtained from parent groups, committee members, friends, special educational schools, public health nurses, local community-based services, and developmental centers, etc. A letter introducing the Pilot Parent Program and inviting them to become pilot parents should be sent to those parents recommended. (See Appendix 1.)

In recruiting future pilot parents, some qualities to look for are:

1. good personal and family adjustment;
2. acceptance of their handicapped child, with realistic expectations for his or her future;
3. involvement in services for their child;
4. acceptance of all handicapped persons (attitude);
5. willingness and ability to share their experiences with new parents and interested persons;
6. willingness to learn about other handicaps.

Further qualities desired are explained in the screening instrument. (See Appendix 2.) This tool may be used to determine the readiness of the prospective pilot parent to work in the Program. Together or separately, at least two persons from the steering committee should interview each set of parents. However, the use of the screening tool is optional, and one may prefer to use his or her own judgement or the recommendation of the local ARC or other Developmental Disabilities Agency. Basic information is gathered pertaining to the parents when they apply to become pilot parents. (See Appendix 3.) This information is retained for use when matching Pilot Parents with new parents who are referred to the Program.

If at some point after the screening interview, the interviewers judge a couple not ready to take part in Pilot Parent training, they should offer alternatives, not rejection. The parents can participate in various alternatives to Pilot Parents such as membership in any voluntary organization that relates to their child's handicap, attendance at various Pilot Parent social events and educational opportunities. These activities can enable them to learn about and adjust to their child's handicap, and hence become ready to attend Pilot Parent training at some later date.

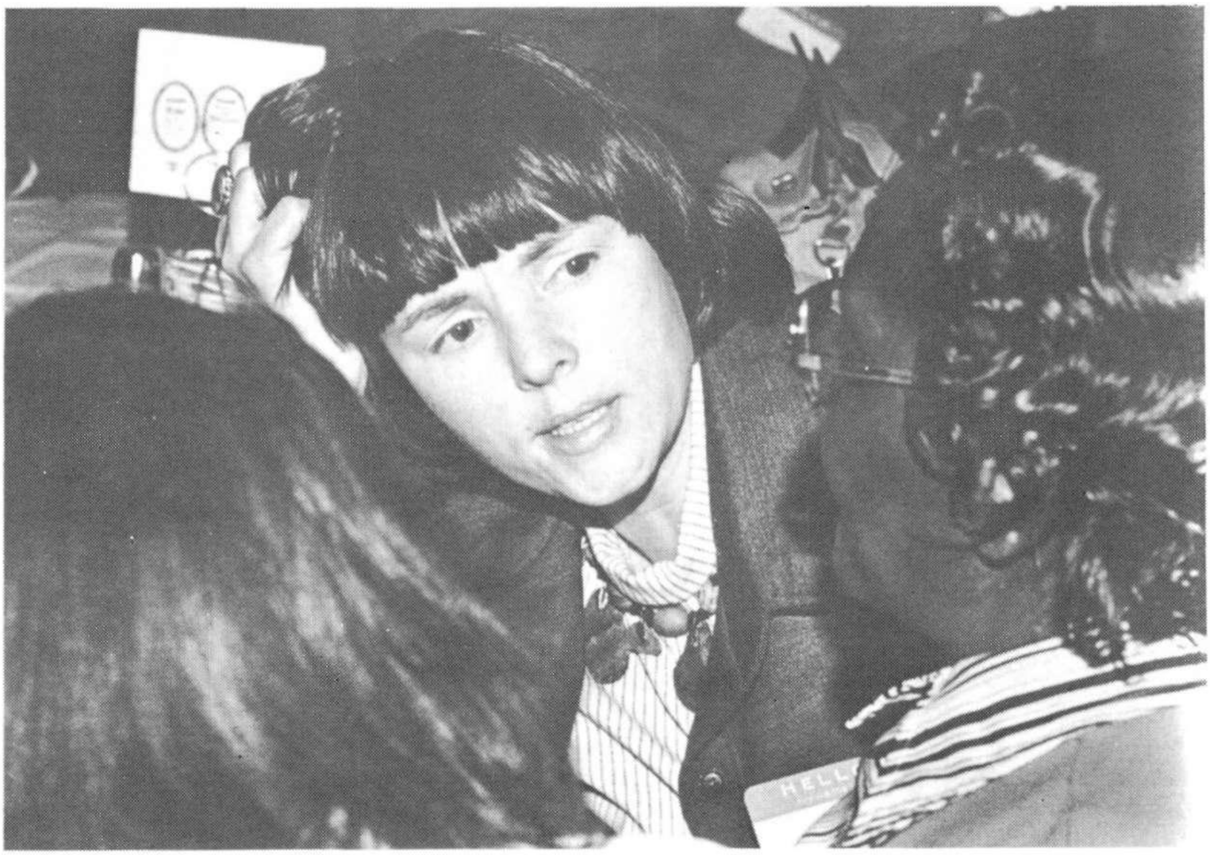
A diversified group of parents is essential to a well-rounded program. One must consider and involve as much as possible families from all social groups and economic levels, as well as parents from every type of family--two parents, single parent, divorced, foster and adoptive.

Fathers are vital to the Program, and whenever possible should be encouraged to participate as pilot parents. Too often, fathers are overlooked or allowed to stand apart from parenting groups, when in fact the father's acceptance of, and positive relationship with, his child is a major factor in the child's development. The father's active involvement in the program benefits the child directly, and, in the long run, enhances the stability of the entire family.

Occasionally, there will be persons who complete training who are not, in fact, well-suited to be pilot parents. What to do? Actually, most parents who are not ready to be pilot parents screen themselves out at some stage in training. However, those who do stay to complete training but who would not be good pilot parents ought to be able to be part of the group and gain the benefit of the group's support and its sense of belonging. It is probably for these benefits that such parents joined the Program. They should, however, not be given pilot parenting assignments, but should be encouraged to assist and contribute in other areas of the Program such as social activities, reviewing program materials, etc. The Pilot Parent Program, one should remember, is not an exclusive group and strives to include persons of diverse abilities; the cost of that flexibility is an occasional member who, though not active with new parents, can still be part of the Program's active membership.

TRAINING PILOT PARENTS

As mentioned previously, being a parent of a handicapped child is a prerequisite to becoming a pilot parent. In addition, twelve to eighteen hours of training over a four to six week period is recommended. By the end of training, prospective pilot parents must be aware of the responsibilities and limitations of their role as pilot parents. They are not therapists or counselors but rather friends, who give moral support, and who share their knowledge and experience with those who may need it. They should be broadly familiar with the developmental disabilities, and knowledgeable about the programs and services available to handicapped persons. Finally, the pilot parents must be able to voice their own feelings about, and experiences with, their handicapped child, and to project an attitude of acceptance toward the challenge of raising a handicapped child.



The topics discussed during the training are:

1. an orientation to the Pilot Parent Program;
2. "Cry Sorrow, Cry Hope", a film that vividly demonstrates pilot parenting;
3. state, regional and local community services;
4. developmental disabilities;
5. the concept of normalization.

In addition to the above topics, the following "Tips for Pilot Parents" are discussed in detail throughout the training sessions. These tips offer guidance and techniques for pilot parents when they are working with new parents. (See also "Training Session 1: Orientation,"p. 42.)

TIPS FOR PILOT PARENTS

1. When you receive a referral, contact new parents within 24 hours if possible by phone.

   When a person indicates they want to talk to another parent, they are asking for help. They need that contact <u>now</u>, not a week from now. Return their call as soon as possible, within 24 hours. If there is some difficulty, check the phone number or contact the coordinator of the Program. Be prepared for a long conversation. It is a great relief for a new parent to talk to someone who understands their feelings and concerns.

2. Call the Pilot Parent chairperson or coordinator and let them know the new parent has been reached.

   If the pilot parents are busy, or for some reason cannot reach the family, another pilot parent may be assigned. If the family seems to be having a difficult time, this is when the coordinator or chairperson and the pilot parent may decide on what special services may be needed.

3. Tell the chairperson or coordinator "no" if you cannot accept the referral.

   This will permit the selection of another pilot parent who will contact the family immediately rather than waiting until you are able to.

4. Do not be afraid to ask for a change in pilot parent, if, after contacting the new family, you feel you cannot relate to them.

   It is better to change pilot parents than to fail to give the support needed due to a conflict of personalities.

5. Occasionally two sets of pilot parents will be assigned.

   When the new family's child has multiple handicaps or a complex one, an inexperienced pilot parent whose child has similar handicaps may be coupled with a more experienced pilot parent, even though their child has a different handicap.

6. Do not be critical or judgemental.

   Pilot parents should not be critical or make a judgement of a family's home, furniture, housekeeping, or personal appearance. The only thing to be concerned with is the family's adjustment to their child and the obtaining of service for their child.

7. Do not give advice.

   Pilot parents are not professionals. Do not give specific instructions; give several suggestions and leave final decisions to the parents.

8. Listen to what the new parent has to say.

   Allow the new parents to express their feelings and ask questions. Do not overwhelm them with your experiences, suggestions, and general information. Let the new parents vent their emotions.

9. Don't be too positive in your attitudes when a family has just learned their child is handicapped.

   When talking to a new family, be reassuring, but do not be too enthusiastic about your child. It may be some time before they will be able to accept the thought that raising a handicapped child has its pleasures and rewards.

10. Don't be too positive about specific services. Try to keep an open mind about the services.

    If the pilot parent is too positive about a specific service the parent may be made to feel they have made a poor choice if theirs is not the same. There may be unknown reasons why they cannot select the same service as the pilot parent.

11. Be sure to relate to baby or child when visiting a family.

    Hold and play with the child. If the child is obviously handicapped you may be the first to relate positively other than the family.

12. Visit and take pictures with you.

    When visiting new parents for the first time have a few pictures of your child from birth to the present with you. New parents are anxious to see how other children with the same handicap look when they are older.

13. Leave a book, preferably a hardbound one.

    This is a good way to assure at least two personal contacts with the new family. You must return to get the book.

14. Encourage parents to take pictures of their child.

    An opportunity once lost can never be regained. Regardless of what they think their child looks like, encourage parents to take pictures right from birth.

15. Take new parents to the services if need be.

    A new parent may need transportation to a service, or perhaps may need moral support to get there. If necessary, accompany them rather than have them miss a appointment.

16. Be a crutch for your new family.

    A pilot parent can be a "crutch" for the new family by offering the support needed until they are able to cope with the situation. However, care should be taken to prevent the family's becoming dependent.

17. Pilot parents help new families to make new friends.

    Many times friends will stop associating with families when a child is diagnosed handicapped. Through the pilot parents and the Pilot Parent Program new friendships can be developed.

18. There will be many contacts with the new family in the beginning; however, they should decrease as the family becomes able to function on their own.

19. Pilot parents help new parents with new medical terms and vocabulary.

20. Do not allow the new family to drain you.

    If they have emotional problems, a new family can become too dependent and demand too much from you. Discuss this with the chairman and/or coordinator. It may be they need professional help.

21. Commit yourselves to Pilot Parents for one year.

    Pilot parenting can be very time consuming; therefore, a commitment for only one year is asked. However, it is not compulsory to leave, and you can remain with the Program as long as you wish. One year at a time.

22. Physicians' packets are available for pilot parents to give to their personal doctors.

    Chairman or coordinator: Discuss contents of the packet and explain whom to contact to obtain one.

23. Pamphlets are free of charge.

    More of the pamphlets contained in the packet for new parents are obtainable from the chairman or coordinator. Always have a supply on hand.

24. Don't worry about delay in obtaining referrals.

    Pilot parents are matched with new families. This occasionally results in some pilot parents receiving several referrals while others have yet to be assigned one. Be patient. Your time will come.

25. Pilot parents are expected to attend monthly meetings.

    Monthly meetings are held to continue education, keep abreast with community services, and share experiences. These meetings should be held on the same evening each month, perhaps the same evening as the training sessions.

26. If you meet a new family in the community, inform the chairman or coordinator.

    This is to assure that the parents are not contacted by several persons from the Pilot Parent Program.

Following training, pilot parents meet monthly to continue their education in new community services and research. Monthly meetings also afford the opportunity for the pilot parents to compare notes, share experiences, and become better acquainted with each other.

The process of training pilot parents is dealt with more completely in Part II, beginning on page 38.

REFERRALS

Initially, referrals to the Program will come from friends, relatives, local community-based services, and other parents of handicapped children. As the Program becomes better known and accepted, teachers, hospital social services departments, nurses, public health nurses, and private physicians will make referrals in addition to those sources already mentioned.

Select a specific telephone number for publication: choose either the number of the sponsoring agency or that of one member of the committee responsible for receiving the referral calls.

Through experience it has been found that the assignment committee is more efficient if comprised of two persons, preferably members of the steering committee.

When a referral is received, the same general information is obtained from the new parent that was obtained from the pilot parent. This is used for matching. (See Appendix 4.)

If the sponsoring agency receives the referral, it is forwarded by phone to the assignment committee. The assignment committee evaluates the referral and selects the most appropriate pilot parents. The pilot parents are then notified and given all pertinent information regarding the new parent. They then contact the new parent usually by phone. It is the goal of the Pilot Parent Program that the new parent be contacted by the pilot parent within 24 hours of the time that their referral call is received.

The person accepting the referral confirms that the new parents are familiar with the Program and have indicated they wish to talk with a pilot parent. No pilot parents are assigned if the parents are not aware of the Program or have not indicated that they want to speak to a pilot parent. No anonymous referrals are processed.

MATCHING

The pairing of new parents with pilot parents is accomplished through the process of matching. When a referral is received the following information is obtained:

1. child's handicap (mental retardation, cerebral palsy, epilepsy, autism, etc.);
2. severity and cause of child's handicap;
3. age of the handicapped child;
4. marital status of parents;
5. age of parents;
6. family structure (number in family, ages of children);
7. geographic area of residence.

The same information was obtained from the pilot parents at the time they completed the application to become members of the Program.

Ideally, families are matched from the above factors. Generally, the more they have in common, the easier it is for them to relate to each other. It is not usually possible or even necessary to match families on all of the above factors. The factors can be used as guidelines and are in priority order, with the type and severity of the child's handicap being the most important consideration. Occasionally, it is impossible to match families based on the child's handicap. If this is the case, a pilot parent can, nevertheless, be very helpful and supportive to the new parent. What the new parent needs, if a precise match of handicap is not possible, is an understanding listener capable of giving guidance and emotional support.

The assignment committee must pay special attention to avoid the matching of new parents of children who are not mentally retarded with those whose children are mentally retarded, regardless of the secondary handicap. Parents of non-mentally retarded children, such as children with cerebral palsy, at times feel threatened that mental retardation is a possibility or perhaps a certainty, if they are paired with a parent of a retarded child.

In rural communities or areas that do not have many pilot parents, matching may not be possible. However, it is useful to have the process available to be used as a guide in order to make the best possible match.

Occasionally, a pilot parent may not wish to accept the referral or a pilot parent may feel unable to assist the family. In such a case, another set of pilot parents may then be assigned. No one should feel obligated to take a referral.

At times it may be advisable to assign two sets of pilot parents to a family. Two sets of pilot parents may be assigned if the multiple handicaps of the child would require the experience of more than one set of pilot parents, or if the pilot parent is inexperienced and needs the support of a more experienced pilot parent. It is possible, too, that a special consideration, such as the new parents' ethnic background, or their connection to the Armed Forces, may lead the assignment committee to assign a second parent who might be especially compatible with the new parents.

SOCIAL EVENTS

Many times, when parents are told their child is handicapped, they feel confused, frustrated, and uncertain. As a result there is a tendency to withdraw into themselves, away from family and friends. At the same time, friends, unfamiliar with handicapped children and not knowing how to respond to the child, may also withdraw from the family. Consequently, social activities are regarded as a very important part of the Pilot Parent Program, for they enable new parents to come out of their isolation into a relaxed atmosphere where people definitely will understand their feelings about their child.

Social activities present the opportunity for new parents to meet other parents of handicapped children, to make new friends, and to share experiences. Social activities allow the new parent to observe (1) how the handicapped child has been integrated into the family of the pilot parent, (2) the acceptance of the handicapped person by the rest of the family, (3) the discipline employed, and (4) the parents' expectations of the handicapped child. Social activities allow all members of the new family to observe the experienced family's situation, and give them an opportunity to organize and evaluate their feelings about the handicapped member of their family, thus assisting the entire family to adjust emotionally.

Summer picnics, ice cream socials, Christmas parties and backyard gatherings bring entire families together. Morning coffees, weekly films, and morning growth groups with guest speakers bring mothers and young children together. Evening discussion groups, with guest speakers, films, etc., and "parent only" parties are good ways to include both parents. Every effort must be made to include fathers in the social activities. Generally, fathers have a more difficult time accepting their handicapped child, and pilot parent fathers give them someone to talk to who understands their feelings.

Although the steering committee member assigned the social activities is responsible for the programs, such activities are much more successful when many of the Pilot Parent group are involved in the planning.

PUBLICITY

An energetic, ongoing publicity campaign is vital to the development and growth of the Program. The general public, parents of handicapped persons, professionals, and service providers must be made aware of the existence of the Program. It is essential that the entire steering committee and all pilot parents participate in this area.

Brochures describing the Program are an excellent means of publicizing the Program. Doctors' and dentists' offices, churches, and hospital lounges are excellent places to have them on hand. (See Appendix 5.) Posters and pamphlets displayed in public buildings, hospitals, medical offices, and businesses are another way of alerting the public to the Program. (See Appendix 6.) The "Social Services" section of the Yellow Pages will provide the names of many agencies and groups who will post Pilot Parent materials for their clientele. One should not forget to alert the local "Welcome Wagon" to the Program's existence, and supply them with materials. Make sure, too, that the Pilot Parent Program is listed in the Yellow Pages.

Letters describing the Program and packets explaining developmental disabilities should be sent to local physicians and pastors. (See Appendices 7 and 8.) The same letters and packets may be sent or taken by pilot parents to the Obstetric and Pediatric Departments of local hospitals. (See Appendix 9.) When pilot parents speak to the staff and members of the local developmental disabilities offices, brochures and letters of introduction to the Program may be circulated. The local school administration and PTAs should be included on the mailing list. (See Appendix 7.)

Television and radio stations are required to devote a portion of their programming day to Public Service Announcements. They are usually quite receptive to Public Service Announcements which reflect local groups and their concerns, and hence can be very helpful in publicizing the Pilot Parent Program, particularly if the pilot parents themselves participate in making the contacts with the station personnel. Local radio and television talk shows are another possibility which can easily be overlooked, but which are accessible to a Pilot Parent Program. (See Appendix 10.) When appearing on television talk shows, do take your child with you, if appropriate. People are really interested in seeing your child; you should check with television personnel about the feasibility of doing so.

Developing a slide film presentation describing the Program in pictures and sound is an excellent method of explaining the Program fully and dramatically to various public audiences. (See Appendix 11.)

THE ROLE OF PROFESSIONALS

Professional consultants can be of real benefit to the Program. Many times families have problems which are beyond the scope of the Pilot Parent Program. A consultant would be able to give professional advice, or refer the pilot parent to the proper resource for services needed by the new family.

As the consultant will be a busy person, assisting the Pilot Parent Program in a voluntary capacity, it might be well to appoint a specific person to be the contact person between the consultant and those pilot parents needing this kind of assistance. A line of communication will be developed which may not be there if calls were made by numerous persons.

A local psychiatrist or psychologist, a physician, a social worker in a local community program, or perhaps a member of the clergy—to name a few—will often accept invitations to be consultants if asked. A much broader role of contributing to the Program's development and its ongoing operation is available to these same professionals. They should remember, however, that the primary forces behind the Pilot Parent Program are the parents themselves and that their ability to provide leadership is the rationale, the method, and the goal of the Program.

AGENCY SUPPORT

If the Pilot Parent Program is sponsored by a parent group or a human service agency or any established organization, support may be in the form of:

1. secretarial duties—typing, duplicating, phoning, ordering reading materials or publications, arranging for meeting facilities, obtaining films, slides, projectors;
2. finances—the agency may provide funds for postage, brochures, pamphlets and other reading materials, film rental, etc.;
3. providing speakers for the training sessions;
4. providing names of parents to become pilot parents.

It is possible, however, to operate the Pilot Parent Program on an entirely volunteer basis. Many films, brochures, and pamphlets are free of charge. These are obtainable from the U.S. Government Printer and the various developmental disabilities agencies. Meeting space will frequently be donated by banks, churches, libraries, and community organizations who have available space. Various mental health professionals are often happy to address a Pilot Parent group if the subject is within their area of knowledge. Students will sometimes donate their work on audio/visual presentations, brochures, etc., in exchange for experience and credit. In short, the resources for an active program are available, if you ask.

COORDINATOR

As the Program develops and grows, the time may come when the volunteers no longer are able to meet the increasing demands of operating the Program. To facilitate further growth, the steering committee may consider hiring a coordinator. With the addition of a coordinator, the steering committee will be relieved of many of its duties, and take on an advisory role.

The coordinator would carry out the directives of the steering committee in coordinating activities in the following areas:

1. publicity and public relations;
2. locating and screening prospective pilot parents;
3. conducting training sessions;
4. referrals and assignments;
5. developing materials for dissemination of information about the Pilot Parent Program to other communities;
6. develop educational programs for pilot parents and new parents.

The steering committee, while relinquishing many of their responsibilities, would continue to function in the areas of chairperson of the committee, secretary, and coordinator of social events. The remaining members of the committee assume chairpersonship of special events as they are planned. The steering committee continues to assist the coordinator in planning the future direction of the Program.

It is a definite asset for both the coordinator and the Program, if the person hired for the position is the parent of a handicapped child. Instances have arisen in Omaha when parents of handicapped children would not talk to representatives of local service agencies. They would, however, speak with the Pilot Parent Coordinator because she is a parent of a handicapped child.

FUNDING

The Pilot Parent Program is designed to be operated on a totally volunteer basis with little or no funding. When the Program is sponsored by a local parent group or organization, funding may consist of the costs for stationary, postage, clerical help (typing, etc.), telephone, purchasing pamphlets for which there may be a small charge; and perhaps, reimbursement for transportation (for low-income pilot parents), cost of renting films, etc., and refreshments for training sessions. However, if a coordinator is employed, additional funds must be obtained. If the sponsoring group is unable to provide these additional monies, other sources of funding must be researched.

The Omaha Pilot Parent Program has received a grant from Developmental Disabilities, Office of Human Development, Department of Health, Education and Welfare Region VII, and also the Developmental Disibilities Office for the State of Nebraska. Copies of these grant applications are available upon request. Contact: Pilot Parent Program, Coordinator, 3212 Dodge Street, Omaha, Nebraska 68131, phone (402) 348-9220.

Other possible sources of funding which may be explored are university affiliates, private foundations, local philanthropists, or United Way funds. Human service agencies, developmental disabilities offices, and other organizations may be useful sources of information about funding and grant sources.

RECORD KEEPING

A Pilot Parent Program should maintain records of the development and operation of the Program. From the files of each member of the steering committee, and especially the chairperson, the committee should be able to provide a detailed annual report to the pilot parents and to the sponsoring agency.

The reasons for detailed record keeping are several. First, the committee and the Program are accountable to its membership and the sponsoring agency; records and data are hard evidence of what the Pilot Parent Program is doing. Secondly, the ability to provide complete records is an indicator of the Program's stability, and does help to establish credibility with those professionals who offer services to parents of handicapped children. Thirdly, in the event that funding is desired, detailed records of the program can mean the difference between full and token funding. Finally, records can facilitate the daily operation of the Pilot Parent Program. Whether finding a speaker on a certain subject, a contact person at a particular agency, or making pilot parenting assignments, records are invaluable.

Begin keeping records from the outset, at the first organizational meeting. (For examples of records to be kept, see Appendix **12.)**

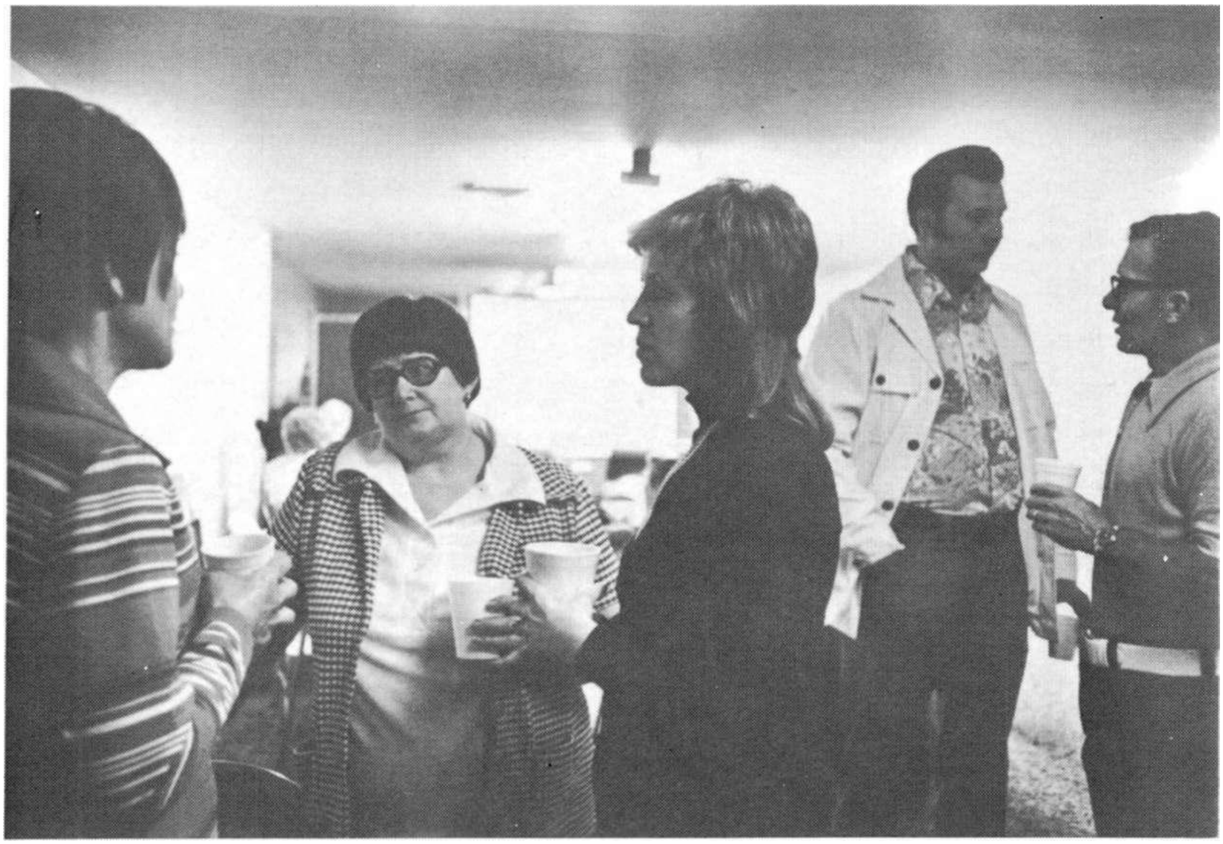
PART II: TRAINING PILOT PARENTS

INTRODUCTION

The materials and information contained in this part of the training manual have been compiled during six years of training pilot parents in the Omaha area. They are offered here only as a guide. Although the topics listed meet the needs in the Omaha area, changes may be necessary to meet the needs of other communities. (See Appendix 13 for sample comprehensive training schedules.)

PLANNING A TRAINING SESSON

Pilot Parent training sessions and meetings demand more care and planning than a beginning group might assume. The meetings should facilitate learning, for there is indeed much to learn. The meetings should be emotionally satisfying: those who attend should feel free to speak of their hopes, fears, and anxieties, and it is important that the location, structure, agenda, and timing of the session be smooth and apt enough to permit honest and personal expression. A huge auditorium in which people sit in rows, for example, would hardly provide the intimacy or face-to-face contact that could enable individuals to voice their feelings. A different kind of obstacle would be the lack of an agenda: it is unlikely that people will speak of their lives and their children if there is no obvious time during the meeting when they know that expressing such matters is appropriate. In short, plan for a setting that is relaxed and comfortable, close but not oppressive, with an agenda that is well-organized but not rigid. Plan, too, for a coffee break to allow people to meet and talk in a more personal way.



Though it may seem overly detailed and specific, the following checklist is designed to insure that the training session or meeting is smooth and purposeful, with no breakdowns, equipment failures, or unforeseen happenings.

1. Decide on appropriate topics to be used in training. Choose appropriate educational materials. (See Appendix 14.)
2. Select night for training sessions. It is advisable to continue monthly meetings on this same evening.
3. Contact speakers for the training sessions.
4. Locate films and other materials pertinent to the topics selected.
5. Prepare an outline of the training session and mail it to all participants.
6. Prepare agenda for each training session.
7. Prepare packets for pilot parents.
8. Prepare new parent packets.
9. Establish starting and ending times of sessions, allowing for a break time during meeting. Also allow time for visiting before and after meeting.
10. Confirm speakers a day or two before sessions.
11. Call all participants on day of session to confirm their attendance.

Further suggestions are:

1. Locate wall plugs and light controls.
2. Locate extension cords.
3. Locate adapter for wall plug.
4. Check film projector.
5. Have extra take-up reel, check size for film showing.
6. Check light bulb on projector and any other light bulbs that are necessary.
7. Check or focus the film.
8. Check film for breaks, etc.
9. Check slide projector.
10. Check operation of slide projector and focus.
11. Locate projection screen.
12. Prepare an agenda.
13. Mail agenda to all participants.
14. Prepare the folders, pamphlets, etc., for pilot parents.
15. Have an attendance sheet.
16. Have name tags.
17. Coffee and refreshments.
18. Confirm speakers.
19. Have ashtrays, and select site where smoking is permitted.
20. Have sufficient seating (make sure there are enough tables and chairs).
21. Be sure someone knows how to operate the projector.
22. Locate and obtain the films.
23. Obtain sound system if needed.

TRAINING SESSION 1: ORIENTATION

The purpose of the orientation is to explain:

1. the function of the Pilot Parent Program;
2. the reason for its development;
3. the need for such a program in the area;
4. the commitment the parents make to the program;
5. the benefits of being associated with the program.

The chairperson welcomes everyone, then gives a brief family history, describing his or her child and the child's handicap, and explaining his or her family's involvement in the Pilot Parent Program. Each person present also gives a brief description of themselves and their handicapped child, and why they are interested in Pilot Parents. The chairperson then asks each person to answer the following questions:

1. When was your child diagnosed as handicapped (what age)?

2. When did you first meet another parent of a handicapped child?

3. When did your child begin receiving services?

While answering the three questions the parent shares with the group his or her past experiences and feelings. It may occasionally be necessary for the session leader to draw out the feelings and details of the experiences of some people. He or she must do this tactfully and supportively. It is important that prospective pilot parents understand, and be willing to verbalize, their feelings and experiences regarding their handicapped child. Hence, he or she should be guided to give a reasonably full account in answering the three questions. This sharing is very important for it enables the members of the group to become better acquainted with each other, and to understand and empathize with each other's feelings. From this understanding develops a cohesiveness which continues to grow as the training continues.

After this mutual sharing of experiences has been completed, the chairperson, or some other appropriate person, should explain the history of the Pilot Parent Program, its goals and its methods, and its relevance to the persons present.

After the coffee break, the trainees view the slide presentation "Growing Together," which describes the Omaha Program. Following the slide presentation, the operation of the Pilot Parent Program is discussed:

1. where referrals come from;
2. how they are processed;
3. the function of the steering committee and its relation to the coordinator of the Program;
4. breakdown of Program tasks by committees;
5. the commitments parents make to the Pilot Parent Program;
6. the benefits of association with the Program.

The following materials are then distributed and discussed:

1. "Pilot Parents Defined" (See Appendix 15.)

2. "Guidelines for Pilot Parents" (See Appendix 16.)

3. "Tips for Pilot Parents" (see page 19), which may be discussed in full, or a few each evening, as time allows.

4. "Principles for the Operation of Pilot Parent Programs" (see page 13).

5. Packets for pilot parents; explain the contents and suggest reading material.

After the chairperson has answered trainees' questions about the Program, the meeting adjourns.

TRAINING SESSION 2: PILOT PARENTING

The second training session utilizes two excellent film presentations to foster discussion about the process of pilot parenting. After the chairperson has opened the meeting and those present have reintroduced themselves, he or she should make sure that everyone has a copy of "Tips for Pilot Parents," a list of suggestions from the experience of Omaha pilot parents. The list is quite relevant to the discussion of the films.

"Cry Sorrow, Cry Hope" (see Appendix 17) is a 55 minute film portraying the frustrations and emotional difficulties of the Fisher family, who suspect their child Billy is mentally retarded, and finally have the child evaluated. The film very graphically demonstrates a pilot parent in action and what the Program is attempting to accomplish, in the person of former U.S. Attorney General Ramsey Clark, who has a retarded daughter. The information and support he gives to Mr. Fisher is an excellent example of pilot parenting.

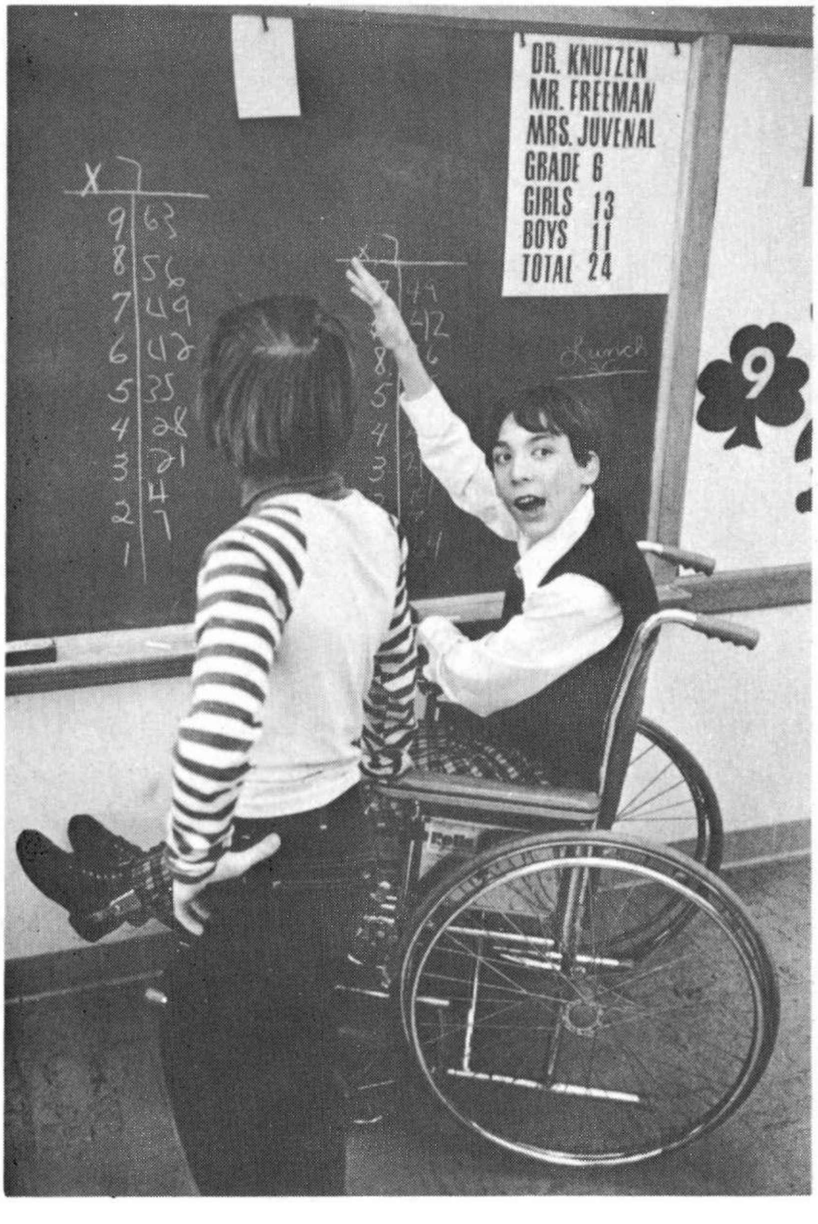
The film "Cry Sorrow, Cry Hope" depicts the impact of one particular handicap—mental retardation—upon the Fisher family. However, the initial feelings of loss, anger, and guilt are common to parents of children with all handicaps. Thus, the film adequately meets the needs of demonstrating what a pilot parent does.

"A Psychiatrist's View of Pilot Parents" (see Appendix 17) is a 15 minute film by Dr. Frank Menolascino, psychiatrist, and associate director of Nebraska Psychiatric Institute of the University of Nebraska Medical Center. Dr. Menolascino (1) gives his interpretation of the film, (2) expresses his feelings about the Pilot Parent Program, and (3) remarks upon the future of programs like Pilot Parents in supporting parents of handicapped children.

After coffee break, the group should discuss the films and should focus in particular on the question, "How does a pilot parent enable new parents to accept their child's handicap?" The films, of course, point to some ways in which parents achieve acceptance. Those present should not, however, overlook their own personal experiences in trying to answer this difficult question.

TRAINING SESSION 3: NORMALIZATION

The purpose of the third training session is to familiarize parents with an important concept formulated with the advent of community-based service systems for handicapped persons.



"Normalization" is a philosophy for the treatment of handicapped individuals which respects them as growing persons; includes them in the normal activities of home and community life; and enables them to learn among their peers those skills and behaviors that best guarantee their acceptance in family and community. Normalization focuses on the handicapped person's skills, rather than on his handicap. Hence, it fosters attitudes and behavior that lead parents to insist that handicapped persons be included in the normal activities appropriate to their age group.

An understanding of this concept can make parents quite sophisticated monitors of programs they may choose for their children. In addition, the concept can make parents more aware of the important effect their own attitudes have on their child's development. (See Appendix 18 for more detailed explanation of the concept.)

TRAINING SESSION 4: DEVELOPMENTAL DISABILITIES

It is important that pilot parents are familiar with each of the developmental disabilities. Two of the remaining three training sessions are devoted to these handicaps, which include mental retardation, cerebral palsy, epilepsy, and autism. Films and slide presentations are available which present good introductory overviews of each disability.

For these training sessions, it is important that the sessions be led by a person qualified to speak knowledgeably on these subjects. Most likely this person will be a physician, psychiatrist, or specialist in one or several of these areas. Each speaker should explain (1) the known causes of the handicap they represent, (2) the effects of the disability on the person, (3) the possible effects of the handicap on the family, (4) current research, (5) services available in the community and how to obtain them, and (6) their agency and its services, purpose, and goals. The session ends with a question and answer period.

TRAINING SESSION 5: SERVICE PROVIDERS

To be effective, pilot parents must also be aware of the services provided in the community. This session is devoted to those in the community who provide services for the handicapped. Directing new parents to the services is a major function of the Program. Representatives of the local agencies discuss their services, who is eligible to receive their services, and how to obtain them. Many of the presenters may have films or slide presentations describing their programs, and should have, as well, pamphlets and written materials to enable pilot parents to understand the special services offered by each agency.
The session closes with a question and answer period.

TRAINING SESSION 6: GRADUATION

On completion of the training sessions, a graduation party may be held to honor the new pilot parents. Certificates are awarded to all those parents who attend three or more training sessions, who now become full-fledged pilot parents. They also receive the packet containing pamphlets and other materials to give to new parents.

The party offers an excellent opportunity for the participants to deepen their acquaintance with others present for the training. Much of the satisfaction of membership in Pilot Parents is the bond that develops between parents, which is maintained through the many social events. The graduation party is indeed one of those events, and care should be taken that the atmosphere is appropriately festive. The Omaha Pilot Parent

Program has usually had a potluck supper or a wine and cheese party as the occasion on which graduation certificates are presented. As the Program grows and the number of pilot parents increases, the party also offers an opportunity for the active pilot parents to become acquainted with the newly trained pilot parents.

Occasionally students in special education, student nurses, counselors and other interested persons will attend the training. However, certificates are awarded to the new pilot parents only, the parents of handicapped children. (Certificate is reproduced in Appendix 19.)

APPENDICES

INVITATION TO PROSPECTIVE
PILOT PARENTS

Appendix 1

Dear

The Pilot Parents of GOARC are planning a new training session beginning in October. Your name has been recommended to us for screening to be a pilot parent. Therefore, we would like to invite you to join us in our efforts to assist other parents whose children have been diagnosed mentally retarded or as having epilepsy, autism, or cerebral palsy to adjust to their problems of having a handicapped member in their family.

Each year we plan to expand the number of parents in the Pilot Parent Program so we can continue to provide assistance for the expanding number of parents who contact us. We are looking for parents who have a good adjustment to their handicapped family member and may now be interested in helping other families who need their help. Brochures are included to explain the Pilot Parent Program.

The screening process consists of interviews with the Coordinator and a pilot parent. We would like to invite you and/or your spouse to make an appointment for this interview. Patty Smith, Coordinator of the Program, will be contacting you for this purpose.

We are setting up a training program of six sessions from October 3 through November 14, 1977 at 7:30 p.m. at the GOARC Office. We meet on the third Monday of each month for our Pilot Parent regular monthly meeting. The regular monthly meeting scheduled for November 21 will be a Wine and Cheese Party for all. These meetings are a combination of education, socialization and the sharing of experiences we have encountered in helping new parents. We are asking for your commitment of one year after training.

We are anxious to meet you. In the meantime we would like to have you fill out the enclosed application and send it to the GOARC Office if you are interested.

Thank you for considering this Program and we hope that you will join us.

Sincerely,

Fran Porter
Co-Chairperson
Pilot Parent Program

Shirley Dean
Co-Chairperson
Pilot Parent Program

FP:job

Enclosures

Appendix 2

PILOT PARENT SCREENING
INTERVIEW

Explain the following to prospective pilot parents:

1. Purpose of Pilot Parents.
2. Screening process.
3. Training sessions.
4. Work with new parents, including contact within one day.
5. Monthly meetings.
6. One year commitment.

Interview Questions:

1. Tell me about your handicapped child.
2. What were your feelings when you found out your child was handicapped?
3. How has having a handicapped child affected your family?
4. What does the future hold for your child when he grows up?
5. Do you think you can be involved with other people without having it hurt you?
6. Are you involved in any parent group or voluntary association?
7. Do you feel you have time to be involved in Pilot Parents?
8. Why would you like to be a pilot parent?

Interview Checklist:

1. Complete the checklist based on the prospective pilot parents' answers to the interview questions.
2. If there were two interviews, checklists are to be compared and responses reconciled between the interviewers.
3. Checklist includes a determination of acceptance to become pilot parents.

4. Regardless of determination, checklists are to be kept and filed.

Notification of Outcome of Screening Process:

The Pilot Parent Coordinator notifies the prospective pilot parents of the results of the screening process.

Appendix 2

QUALITIES/ABILITIES	YES	NO
Ability to cope with other people's problems.		
Willing to become personally involved with other people's problems.		
Can cope with other people's problems without being hurt by them.		
Can handle confidential information without the need to discuss with other people.		
Ability to communicate.		
Express selves adequately.		
Are good listeners.		
Maturity.		
Able to accept rejection by others without being personally offended.		
Can work without a lot of praise or recognition.		
Willing to give to others without expectation of returns.		
Time.		
Have time to be involved in Pilot Parents (based on the judgement of the prospective parents).		

Comments and Recommendations:

Parents should be accepted to become pilot parents. (Yes rating in all of the above areas.)

If not recommended for acceptance into Pilot Parents, what other areas were discussed (in Pilot Parents, voluntary associaton or services):

Appendix 2

PILOT PARENT SCREENING INTERVIEW CHECKLIST

Name of Prospective Pilot Parents: ______________________________

Interviewer: ______________________________ Date: ______________

For each quality/ability, check yes if parents seem to have reached the described level; check no if not.

QUALITIES/ABILITIES	YES	NO
Acceptance of handicapped child.		
View handicapped child as a valuable person.		
Accept child's strengths and weaknesses and have expectations which seem realistic for the child.		
Believe child can learn and view learning opportunities as important.		
Participate actively in services provided to own child (are seeking or have obtained services, participate in and monitor services and advocate for change as needed).		
Have successfully worked through any anger regarding child being handicapped and professionals involved.		
Acceptance of other people who have handicaps.		
Accept other people who have handicaps.		
View all people as valuable.		
Interested in helping other people.		
Believe handicapped people have rights, including the right to live in the community.		
Ability to provide support to other parents.		
Willing to share own experiences.		
Concerned about other people.		
Not judgemental of other people.		
Would view role as supporting other people in their decisions, not assuming a decision-making role.		
Are coping with own family problems well.		
Can identify other people's feelings.		

Appendix 3

Date ____________

APPLICATION FOR PILOT PARENTS

I. FAMILY INFORMATION

Your Name ______________________________ Age ______

Address ______________________________ Phone ______
Number Street City

Education ____________________ Occupation ____________

Place of Employment ______________________________

Interests/Hobbies ______________________________

Your marital status? ___ Separated ___ Married ___ Divorced ___Widowed
___ Single

Spouse's Name ______________________________ Age______

Education____________________ Occupation ____________

Place of Employment______________________________

Interest/Hobbies______________________________

Religion____________________

How would you rate your family's income? ___Low Income ___Low Average
___Average Income ___High Average ___High Income

Name of Each Child	Birthdate	Sex

II. INFORMATION REGARDING HANDICAPPED CHILD

Name of your handicapped child______________________________
Was handicap known from birth? ___ Yes ___ No
If not, since when?______________________________

What was the cause of handicap?______________________________

What is the degree of impairment?
___Mild ___Severe
___Moderate ___Unknown

Appendix 3

Does your child have any other handicaps? ___Yes ___No

If yes, what are they?________________________________

Does this child live at home? ___Yes ___No

If not, where?________________________________

Please list the programs in which this child has participated (starting with this current program).

NAME OF PROGRAM	DATES OF PARTICIPATION

III. PARENTAL EVALUATION

Do you believe that you and your family have made a good adjustment to your handicapped child?

____

____

____

What are your ideas about services for the handicapped in general, and for your child especially?

____

____

____

IV. FACTORS INFLUENCING YOUR DESIRE TO BE A PILOT PARENT

Would you be available to meet with other pilot parents periodically?

___Yes ___No

Would your spouse be available to visit new parents with you during the day? ___Day ___Evening

Would you have your own transportation? ___Yes ___No

Would reimbursement for transportation be a requirement in order for you to participate? ___Yes ___No

Appendix 4

Date ____________________

Name of Pilot Parents

____

Date Assigned________

I. FAMILY INFORMATION

Your Name ____ Age __________

Address ____ Phone __________
Number Street City Zip

Education ______________________________ Occupation __________________

Place of Employment ____

Interests/Hobbies ____

Your marital status? ___ Separated ___ Married ___ Divorced ___Widowed
___ Single

Spouse's Name ____ Age____________
Last First

Education ______________________________ Occupation __________________

Place of Employment ____

Interest/Hobbies ____

Religion ____________________________

How would you rate your family's income? ___Low Income ___Low Average
___Average Income ___High Average ___High Income

Name of Each Child	Birthdate	Sex

II. INFORMATION REGARDING HANDICAPPED CHILD

Name of your handicapped child ____

Was handicap known from birth? ___ Yes ___ No
If not, since when? ____

What was the cause of handicap? ______________________________________

If mentally retarded, what is the functioning level of this child?
___Borderline ___Moderately ___Profoundly retarded
___Mildly retarded ___Severely retarded ___Unknown

PILOT PARENTS believe that offering emotional support and factual information about a child's handicap enables parents to view, in a positive manner, their child's ability to grow, learn, and develop to his fullest potential.

PILOT PARENTS offer . . .

- ...emotional support and understanding;
- ...factual information about developmental disabilities;
- ...factual information about medical services, educational programs, and supportive agencies;
- ...introduction to helpful persons and groups that share their interests and concern.

The PILOT PARENT PROGRAM serves parents of all children with developmental disabilities.

PILOT PARENT PROGRAM
3212 Dodge Street
Omaha, Nebraska 68131
(402) 348-9220

A Program sponsored by the
Greater Omaha Association for Retarded Citizens

Parents of Handicapped Children

HELPING

Parents of Handicapped Children

The **PILOT PARENT PROGRAM** is a program in which parents of handicapped children help parents who have recently learned that their child has mental retardation, cerebral palsy, epilepsy, or autism.

PILOT PARENTS • PROGRAM •

PILOT PARENTS have had the experience of learning their child is handicapped. They have asked many of the same questions that "new parents" ask.

PILOT PARENTS have learned, through their personal experiences, that raising a handicapped child can be rewarding.

PILOT PARENTS have taken training to enable them to assist and guide "new parents" of handicapped children.

If you have a handicapped child and would like to talk to another parent, please call. A PILOT PARENT with similiar experience and background will contact you.

Parents of Handicapped Children
HELPING
Parents of Handicapped Children

If you know of someone who could benefit from talking to a parent, please call. PILOT PARENTS are available to assist "new parents" in person or by telephone. They are also available to visit with other family members.

"The Pilot Parent Program has filled a tremendous void in our lives. Our son had every professional available to meet his needs. We as parents had nothing. Pilot Parents provided us with an opportunity to meet and talk with other parents who knew and understood all our feelings both good and bad, and could relate to our hopes for him".

Janie Grimm Pilot Parent

"After we learned our child was handicapped we felt alone and isolated. The most important thing our Pilot Parents did for us was to share their experience and allow us to express our feelings with people who could understand what we were going through".

Mary Jo Simpson New Parent

"From my exposure to the Pilot Parent Program, I have consistently found it to be a most innovative and effective aid to parents of handicapped children".

Frank J. Menolascino, M.D.
Past President of the National
Association for Retarded Citizens

"As a father of a multi-handicapped son, I see a definite need for a husband's active involvement in Pilot Parents. It is often the husband who is withdrawn and does not associate with his child or aid in obtaining services for him. Another father can offer the "new father" the emotional support and assistance he needs in this time of crisis".

Larry Heeren Pilot Parent

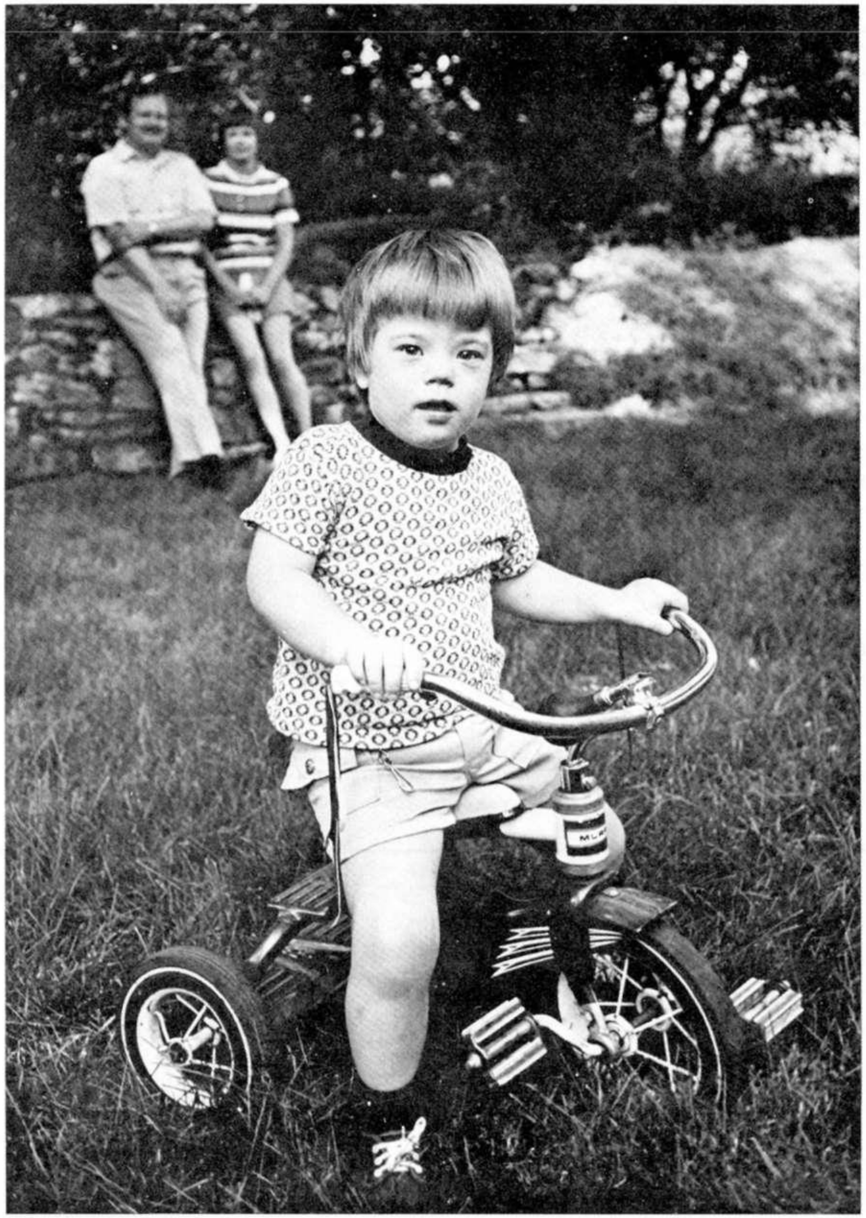
"Pilot Parents gives us the continuing opportunity to share our experience with others, and help make the thought of raising a handicapped child less threatening".

Jane Upton Pilot Parent

"The Pilot Parent Program is by far one of the best run and most effective operations of its kind in the Nation".

Robert Perske
President's Committee
on Mental Retardation

Appendix 6



photograph by Robert Coleman

If your child is handicapped, he needs all the help he can get.

You, the parent, can help him the most by

- Having positive attitudes about him and his abilities;
- Knowing what services he may need, and where to obtain them;
- Knowing how to help him learn at every opportunity.

The handicapped child can overcome, if you teach him how.

For more information call:

Pilot Parent Program
Greater Omaha Association for Retarded Citizens
3212 Dodge Street
Omaha, Nebraska 68131
348-9220

Appendix 7

INITIAL INTRODUCTORY LETTER TO PHYSICIANS

Dear Physician:

Allow us to introduce ourselves. We are the Pilot Parents of the Greater Omaha Association for Retarded Citizens. This means we are parents of handicapped children who have had some measure of success in handling this problem in our own families. Because of our experience with this problem we have some understanding of what parents go through when they first learn that their child is handicapped. For this reason we want to be available to parents who struggle with this same problem.

We have undergone a period of training. However, we are not therapists nor counselors and are not interested in formal referrals. We only ask that you pass out the attached brochures to parents who may be interested in friendly visits with another parent of a handicapped child. Feel free to place these brochures in your reception area.

If you would like further information or more brochures, please call the GOARC Office, 348-9220.

We have learned how valuable it is to talk with other parents of the handicapped who have befriended us. We want to be helpful friends to any of your parents in similar circumstances who would seek us out.

Sincerely,

Fran Porter
Co-Founder
Pilot Parent Program

Shirley Dean
Co-Founder
Pilot Parent Program

FP:job

INITIAL INTRODUCTORY LETTER
TO SCHOOL OFFICIALS

Appendix 7

Dear PTA President:

Allow us to introduce ourselves. We are the Pilot Parents. This means that we are the parents of handicapped children who have had some measure of success in handling this problem in our own families. Because of our experience with this problem, we have some understanding of what parents go through when they first learn that their child is mentally retarded, epileptic, cerebral palsied or multi-handicapped. For this reason we are available to parents who struggle with these same problems.

We have undergone a period of training. However, we are neither therapists nor counselors; we are parent helpers. We provide emotional support, factual information, and direction to services for these families.

Enclosed is our brochure explaining the program. We have a group of parents who are willing to speak before any parent group. They will describe our program and share their experiences in regard to the pilot parenting.

Please contact our Coordinator, Patty Smith, at the GOARC Office, 348-9220, to make program plans. She is available to assist you in any way regarding the Pilot Parent Program.

Sincerely,

Fran Porter
Co-Founder
Pilot Parent Program

Shirley Dean
Co-Founder
Pilot Parent Program

FP:job

Enclosure

INITIAL INTRODUCTORY LETTER TO CLERGYMEN

Appendix 7

Dear Pastor:

Allow us to introduce ourselves. We are the Pilot Parents. This means we are parents of handicapped children who have had some measure of success in handling this problem in our own families. Because of our experience with this problem we have some understanding of what parents go through when they first learn that their child is mentally retarded, cerebral palsied, epileptic, autistic, or multi-handicapped. For this reason we want to be available to parents who struggle with these same problems.

We have undergone a period of training. However, we are not therapists nor counselors. We are parent helpers. We only ask that you pass out the attached brochures to parents who may be interested in friendly visits with another parent of a handicapped child. Feel free to place these brochures in your reception area.

If you would like further information, please call our coordinator, Patty Smith at the GOARC Office, 348-9220 (her business card is also enclosed). Also, our parents are available to speak to groups about the Pilot Parent Program.

We have learned how valuable it is to talk with other parents of the handicapped who have befriended us. We want to be helpful to any of your parents in similar circumstances who would seek us out.

Sincerely,

Fran Porter
Co-Founder

Shirley Dean
Co-Founder

FP:job
Enclosures

SECOND LETTER TO PHYSICIANS WITH SUPPORT OF SERVICE AGENCY

Appendix 7

Dear Doctor:

At the suggestion of, and with the approval of, the Executive Board of Directors of the Omaha Medical Society, the parents of the Greater Omaha Association for Retarded Citizens and the professionals of ENCOR are taking this means of announcing the development of an informational packet on mental retardation, including pamphlets on specific causes and problems.

This packet, in a form suitable for filing, is being offered free of charge, to all members of the medical profession in the greater Omaha area. It is our sincere hope that each of you will find its contents useful and will distribute the appropriate pamphlets to parents when you inform them their child has been diagnosed mentally retarded.

Enclosed is a card for your convenience. If you wish to receive one of the packets for your files, please return the enclosed card with your name and address.

Sincerely,

Gary Taylor
President
GOARC

Kevin Casey
Executive Director
ENCOR

This packet includes the following materials:

- SIBLINGS OF THE RETARDED
- NEEDS OF PARENTS OF MENTALLY RETARDED CHILDREN
- THE PARENTS OF RETARDED CHILDREN SPEAK FOR THEMSELVES
- FLYER ON BOOK ENTITLED "NEW DIRECTIONS"

Information Pamphlets on:

- ENCOR
- GOARC
- MCRI
- PILOT PARENTS
- NARC
- DEVELOPMENTAL DISABILITIES
- TOY LENDING LIBRARY
- NARC PUBLICATION LIST
- INTO THE LIGHT OF LEARNING
- TOILET TRAINING YOUR RETARDED CHILD

JG:job
Enclosure

THIRD LETTER TO PHYSICIANS WITH UPDATED PAMPHLET PACKET

Appendix 7

Dear Doctor:

At the suggestion of, and encouragement of many of the agencies with whom Pilot Parents are associated, we are taking this opportunity to announce an update offering of an information packet on developmental disabilities, including pamphlets on the specific disabilities.

This packet, in a form suitable for filing, is being offered free of charge, to all members of the medical profession in the Greater Omaha area. It is our sincere hope that each of you will find its contents useful and will distribute the appropriate pamphlets to parents when you inform them their child has been diagnosed developmentally disabled.

Enclosed is a Pilot Parent business card. If you wish to receive one of the packets for your files, please return the enclosed postcard with your name and address.

Sincerely,

John Glynn
Executive Director
GOARC

Patty Smith
Pilot Parent Program
GOARC

JG:job
Enclosure

Appendix 8

PAMPHLET CONTENTS OF PHYSICIANS PACKETS:

CONTENTS OF PHYSICIANS PACKETS:

Service Providers:
Pilot Parent Program
Greater Omaha Association for Retarded Citizens (GOARC)
Eastern Nebraska Community Office of Retardation (ENCOR)
Childfind
Meyer Children's Rehabilitation Institute (MCRI)
Epilepsy Council of Omaha (ECO)
Nebraska Epilepsy League
United Cerebral Palsy of Nebraska
Visiting Nurse Association (VNA)
Boys Town Institute

Nebraska Association for Retarded Citizens (NARC)

Autism:

Could Your Child Be Autistic?

Epilepsy:
Medical and Social Management of the Epilepsies
Answers to the most frequent questions people ask about epilepsy
Cerebral Palsy:
What is Cerebral Palsy?
Cerebral Palsy - Facts and Figures
Mental Retardation:
Siblings of the Retarded
Needs of Parents of Mentally Retarded Children
The Parents of Retarded Children Speak for Themselves
Flyer on book entitled..."New Directions..."
Toilet Training Your Retarded Child
Meeting the Needs of the Developmentally Disabled Individual

Additional packets and publication lists of each disability are available through the GOARC Office, 348-9220.

INFORMATION SHEET TO BE POSTED
IN HOSPITALS

Appendix 9

A HANDICAPPED BABY

There are perhaps no words to describe the shock and despair which parents feel when they learn that their baby will be handicapped. In years past, parents were usually advised to put their child in an institution where they would be cut off from a normal life. But now, we have learned that, in most cases, the child and the family will be happier and the child develop better if he grows up in his own home.

However, there are stresses to be worked out, hardships to face, and techniques to learn along the way. Parents need help to learn to accept their situation, to learn where to seek professional help, and to learn about the opportunities for the development of their child.

An Information Packet is available from the Pilot Parents of the Greater Omaha Association for Retarded Citizens. It can be given to the parents at the hospital by the hospital personnel. This packet contains basic literature about handicapping conditions and where to seek further information when they want it.

Pilot Parents is a service for parents of children diagnosed mentally retarded, cerebral palsied, epileptic, or multi-handicapped. A parent (who is well-informed and trained) can contact the parents to offer support and friendship at a time when it is most badly needed. The new parents should be asked by hospital personnel if they would like this service. They can also be asked by the Visiting Nurse Association who can call on them when they get home from the hospital.

The Infant Development Program can be started when the baby is a few weeks or months old (depending on the parents' wishes). It is designed to help infants and toddlers with special needs.

These services are available for the asking. Hospital personnel are the first to encounter the family--please help them by contacting the Coordinator of the Pilot Parent Program at 348-9220 or your Visiting Nurse Association, Division of Public Health Nursing Omaha-Douglas County Health Department at 342-0231. This project has been endorsed by the Omaha-Douglas County Health Department.

Pilot Parent Program
140 South 40th Street
Omaha, NE 68131
Phone: 348-9220

Appendix 9

POSTCARD INCLUDED IN HOSPITAL PACKET FOR PARENTS

If you would like to talk to another parent of a child who has a similar handicap to that of your child, call Pilot Parents at 348-9220, or fill in this card, drop it in the mail and Pilot Parents will contact you.

NAME:______________________________________
ADDRESS:___________________________________
CITY, STATE:_______________________________
PHONE:_____________________________________

POSTCARD REQUEST FOR MORE PILOT PARENT MATERIALS

HOSPITAL PERSONNEL

If you would like more Hospital Packets made available to you, please call the Pilot Parent Coordinator at 348-9220 or drop this card in the mail and these additional packets will be sent to you as soon as possible.

NAME:______________________________________
ADDRESS:___________________________________
CITY, STATE:_______________________________
PHONE:_____________________________________

Appendix 10

SPOT ANNOUNCEMENT

THE PILOT PARENT PROGRAM

HAS TRAINED CORPS OF PILOT PARENTS

WHO ARE READY

TO BEFRIEND AND SHARE EXPERIENCES

WITH NEW PARENTS OF HANDICAPPED CHILDREN.

PILOT PARENTS

ARE

PARENTS "WHO HAVE BEEN THERE"

AND NOW STAND READY TO HELP OTHERS WHO NOW FACE THIS SITUATION.

A PILOT PARENT CAN BE CONTACTED BY CALLING PILOT PARENTS AT TELEPHONE NUMBER 348-9220

SPOT ANNOUNCEMENT

IT'S NOT AN EASY THING TO BE THE PARENT OF A HANDICAPPED CHILD.
BUT, IT'S NOT THE WORST THING EITHER.
IN FACT, IT COULD MARK THE BEGINNING OF A CREATIVE FAMILY LIFE.

PILOT PARENTS ARE PARENTS OF HANDICAPPED CHILDREN "WHO HAVE BEEN THERE."
THEY NOW STAND READY TO HELP OTHER PARENTS IN THIS SITUATION.

A TRAINED PILOT PARENT CAN BE CONTACTED BY CALLING THE PILOT PARENT PROGRAM AT 348-9220.

SPOT ANNOUNCEMENT

WHEN PARENTS LEARN THAT THEIR SON OR DAUGHTER IS HANDICAPPED, THEY OFTEN NEED EXTRA HELP TO UNDERSTAND WHAT HAS HAPPENED AND WHAT THEY CAN DO ABOUT IT.

PILOT PARENTS ARE A GROUP OF TRAINED PARENTS WHO ARE WILLING TO OFFER EMOTIONAL SUPPORT, SHARE EXPERIENCES, AND HELP A NEW PARENT FIND SERVICES THEY NEED.

PILOT PARENTS UNDERSTAND WHAT A NEW PARENT IN THIS SITUATION MUST OFTEN GO THROUGH. AND THEY ARE WILLING TO BE AVAILABLE TO OTHER PARENTS IN THIS SITUATION.

A PILOT PARENT CAN BE CONTACTED BY CALLING 348-9220.

Appendix 10

RADIO PUBLIC SERVICE ANNOUNCEMENT

KFAB RADIO "Helping Hand"

GOARC Pilot Parent Program

If you have just been told your child is handicapped and are plagued with feelings of isolation, guilt, and despair, Pilot Parents can help. Pilot parents are parents helping parents of handicapped children. They've been there. They've asked all the same questions — "why me?" They are trained to direct you to services and give you factual information which can help you help your loved one. Pilot parents listen and understand. They're your friends.

Pilot parents have learned through this Program to cope with their problems and are eager to lessen the burden on you. They are not just limited to help those with mental retardation but with epilepsy, cerebral palsy, multiple handicaps, and autism.

The Pilot Parent Program is a program of the Greater Omaha Association for Retarded Citizens, which is affiliated with United Way of the Midlands. There is no charge for the trained parent volunteer.

If you are a parent who knows of someone who has a handicapped child, call the Pilot Parents at 348-9220, and they will get in touch with a trained parent-volunteer who is willing to help you and be your friend.

Appendix 10

RADIO PUBLIC SERVICE ANNOUNCEMENT

KFAB RADIO "Helping Hand"

GOARC

If you are the lonely, frustrated parents of a handicapped child, Pilot Parents can help. Pilot parents are also parents of the handicapped — parents helping parents. They have experienced your despair, your fear, your frantic searching. They, too, have asked, "Why me?" They are trained to direct you to agencies and resources which can help your loved one. Most of all, they listen and understand.

Through the Pilot Parent Program, they have learned to cope with their own problems and are eager to help you. There is no charge for their services.

Pilot Parents is sponsored by the Greater Omaha Association for Retarded Citizens, which is affiliated with United Way of the Midlands. The help offered does not stop with mental retardation. Parents are available to talk to those who have children with epilepsy, cerebral palsy, mental retardation and multiple handicaps.

If you are a parent with a disabled child, call the Pilot Parents office today — 348-9220. They will promptly put you in touch with a trained parent-volunteer who has a similar problem and can help you.

If you know someone who needs help, tell him or her about Pilot Parents. Pilot Parents can change despair to hope. Contact the Greater Omaha Association for Retarded Citizens.

Thank you.

Appendix 10

SAMPLE NEWS RELEASE

The Pilot Parent Program, sponsored by the Greater Omaha Association for Retarded Citizens, will be having their annual Christmas party on December 5, 1976 from 2:00-5:00 p.m. at St. Paul United Methodist Church, Fellowship Hall (5410 Corby).

The program will include: a puppet show, door prizes, presents for the children and, of course, a visit from Santa Claus.

Refreshments have been-donated by McDonald's Restaurant.

For more information contact:

Patty Smith
Coordinator, Pilot Parent Program
GOARC
(402) 348-9220

Send to: KMTV, KETV, WOWT, World-Herald,
and the Sun Newspapers.

Appendix 10

SAMPLE NEWS RELEASE

The Greater Omaha Association for Retarded Citizens announced today that the Pilot Parent Program has been awarded a three year regional grant from the Region VII Developmental Disabilities Office in Kansas City, Missouri beginnng October 1, 1977.

According to Patty Smith, Coordinator of the Program, "the Pilot Parent Program will be serving the four states of Iowa, Kansas, Missouri, and Nebraska. We will be developing ten sites within the first year in this four state area using the Omaha Program as a model. Pilot parents are veteran parents of developmentally disabled children who have taken training to help newly diagnosed, newly identified parents of developmental disabled children." The developmental disabilities include epilepsy, autism, cerebral palsy, and mental retardation.

The program may be reached at 3212 Dodge, Omaha, Nebraska 68131, (402) 348-9220.

Appendix 10

SAMPLE LIST OF NEWS
RELEASE ADDRESSEES

Release sent to:

KETV, KMTV, WOWT
KFAB, KOOO, WOW, KOIL, KRCB, KYNN and KOWH radio stations
Sun Newspapers, World-Herald, UPI, API wire services
Lincoln Journal, Lincoln Star newspapers
C. B. Non-Pareil Newspaper
Nebraska Education News in Lincoln
UNO Special Education Newsletter
All Regional OMR Offices (including ENCOR's Kathy Herro-Nahas)
State OMR Office (Arnold Carmel)
State Department of Vocational Rehabilitation
State Department of Special Education
National Association for Retarded Citizens
Midlands Information and Referral of Nebraska
Amy Bennet - C.A. Program - Kearney State College
Birth Defects Prevention Program
C.A. Services, Inc. (Grand Island)
National Association for Autistic Citizens, c/o Nancy Heller
Epilepsy Council of Omaha
NE Epilepsy League
United Cerebral Palsy
CARC - Betty Younkin C.A. Program
Easter Seals Society
NebARC

Appendix 11

PILOT PARENT SLIDE/TAPE NARRATIVE

"GROWING TOGETHER"

The big question — the one that made it so hard for us when Chris was born—was: what was going to happen to him? . . . .

It's easy to see now that what will happen to Chris will be the result of what we, our family, does with Chris, for him, and how much we let him learn on his own. In other words, it's up to us. In many ways, we're lucky. Chris is learning to do so many things, and Don and I are elated with him. There's no other word for it.

Five years ago was a different matter. There is simply no easy way for a mother to hear "I'm sorry, your child is not normal." It was a devastating shock for us, and for awhile, taking care of Chris was like a nightmare. We felt like we were an island with no contact with the outside world.

Then I met the Shafers, and that changed everything for us. I saw Lila on TV talking about Pilot Parents so I simply called her up and we met. Just seeing Kevin, who is a Down's Syndrome child like Chris, was an overwhelming experience. My whole view of Chris had been negative—I'd been imagining all the things he couldn't do—and because of Kevin, seeing him talk, run, look at books, it all became positive. Suddenly I became aware of what Chris could do, and that shift in our perspective made all the difference for us.

Don and I know that Chris has limits—you never forget them—but we see his achievements, his potential. He is doing some beautiful things at the Montessori School. He even reads, and that astounds us. And he runs and tackles and tumbles just like any other little boy.

Appendix 11

Having Lila and Don as pilot parents helped us tremendously in our attitudes toward Chris. Since then, Don and I have become pilot parents and I think we've grown tremendously from it. I think every parent of a handicapped child ought to have that kind of opportunity—to help other people raise their child better, and to enrich ourselves from knowing people with experiences and feelings similar to our own.

The best part of the Pilot Parent Program is the people; interesting people, warm people who want to believe and who do believe that raising a handicapped child the best way possible is very important.

What binds us together is our interest and shared concern for our children. When you meet someone that you know has worried about their child just as you have, and whom you know wants him to grow up and live on his own in the world, just like you have wished for your child, it's easy to find a common ground for friendship.

Every pilot parent goes through training, eight two-hour sessions, before they begin to pilot a new parent. Most parents know a great deal about their child, but not a great deal about the ideas and concepts behind a system of services that helps many children with different needs. If one is going to help a bewildered parent find services and help for their child, a pilot parent has to understand the system services as a whole and the ideas behind it. Training is a really good experience and an opportunity to meet people who are helpful and knowledgeable.

Appendix 11

Pilot Parents promotes a lot of activities that bring the same people together, and that is part of the reason for its success. There's a summer picnic and ice cream social, a Christmas party—events where both parents and kids can enjoy themselves and meet one another. There are several wine and cheese parties in the course of the year. Parents attend monthly growth groups where, over coffee and donuts and the noise of the kids, they talk over their setbacks and successes in parenting. Pilot Parents is fun, friendship, and learning all tied up together.

So how do I feel after three years of being in Pilot Parents? Enriched. Happy because I've had a chance to help some people adjust to the challenge of raising a handicapped child. Happy because I think that Don and I are better parents to Chris. I never would have thought four and a half or five years ago that I'd be so proud of Chris and so pleased with his development, but I am, and Pilot Parents has helped to get me there.

Appendix 11

The Pilot Parent message very simply is to love and enjoy your child, and treat him or her as a growing and learning person regardless of his or her handicap. Everyone says, "Accept your child's handicap," but really, accepting the handicap means almost forgetting about it, and enjoying the child just as he or she is. That doesn't mean not to teach a handicapped child; a family should include the handicapped child in all learning opportunities. With the right encouragement, a handicapped child will learn some remarkable things.

An attitude like that frees parents from worry and guilt and really enables them to encourage their child to develop and learn. Kevin, Lila's son, is a good example. Born with Down's Syndrome, Kevin now attends Montessori School, is curious, and is learning so many things.

Jane is another example of how parental encouragement and determination to treat their child normally can pay off. Jane attends preschool with non-retarded children, and like so many handicapped children in integrated settings, is accepted beautifully by the other children and learns a great deal from them.

Every parent can learn from other parents. The beauty of Pilot Parents is that it brings people together to learn from each other, to discuss our children and how they're doing or simply to be a friend. Raising a handicapped child intimidates many parents, but when you can see and know parents who've done so well, it gives you the courage to do what you want to do: raise your child, whatever his handicap. It really is courage that other parents communicate to you—the courage to admit that their child is handicapped. The courage to love the child for what he is, the courage to let him learn at his own pace without rejecting him. That quality really comes through from the people I know in Pilot Parents.

It is advisable to have duplicate sets of records. If there are two assignment persons they will each have a set of. records to permit cross checking. If a staff person is doing the assigning, a detailed list in addition to the cards used to obtain the information at the time of referral, provides a means of cross checking, thus eliminating a chance for omitting or losing a referral.

Publicity - Publicity Chairperson
Appendix 2 and 3.

Records on all facets of publicity to promote the Program should be kept.

The following should be noted:

1. agencies contacted and contact person; who the contact person is;
2. social and professional persons, agencies contacted and material sent, material used;
3. media contacted—TV, radio, newspapers — slide/tape presentations;
4. number of requests for presentations—dates and locations, which pilot parents gave presentations;
5. requests for information regarding the operaton of the Program, dates, materials sent, local, state, national or international;
6. contacting state fairs, local conventions, listing contact persons; etc.

This information indicates the growth of the Program, and also provides valuable assistance to future publicity chairpersons.

Appendix 12

SAMPLE RECORDS

Minutes of Meetings - Secretary

The minutes of all meetings—Steering Committee, monthly meetings, or any special meetings—should indicate all decisions of each group, for future reference. The secretary should send copies of the minutes to each person on the steering committee, each of the pilot parents and the Executive Director of sponsoring agency.

Social Events - Social Events Chairperson

These records should include a report on all social activities of the Pilot Parent group:

1. the number of coffees, parties, picnics, etc.,
2. whether they were for pilot parents only or piloted parents also,
3. location and date,
4. the kind of refreshments served,
5. who provided them and cost, if any,
6. in the case of picnics, Christmas party, etc., if prizes were given, the companies who donated them and the person to contact.

This information is invaluable in assisting the succeeding chairperson of this committee to perform his or her duties.

Referrals - Referral Chairperson

The referral records are most important and should indicate:

1. number of referrals received;
2. date received;
3. name of parents (family);
4. name of child;
5. age of child;
6. pilot parent(s) assigned;
7. types of handicaps served;
8. source of referral;
9. follow-up by pilot parent(s).

Appendix 12

Training Sessions and Reports, Chairperson(s)

The chairperson maintains all remaining records. These records pertain to the recruiting and screening of prospective pilot parents; the training sessions, speakers, materials used in training, attendance at the training sessions and the number of trained pilot parents. In addition the chairperson maintains these records:

1. titles of pamphlets and materials used in training; a list of materials available and sources of supply;
2. training schedule and names of guest speakers and agencies represented;
3. the names of possible pilot parents, and the person recommending them;
4. the names and addresses of those parents invited to become pilot parents;
5. all applications received from parents applying to be pilot parents;
6. the results of screening the applicants;
7. the attendance for the training sessions;
8. the names and addresses of all trained pilot parents; the number of parents having taken the training; active pilot parents and inactive pilot parents;
9. the names, addresses and agency represented, of all professionals, students, etc., who have audited the Pilot Parent training.

Appendix 12 a

Date	Name	Address	Phone	Child's Name	Age	Disability	Confirm. of PP Contact	Follow-up

Appendix 12 b

TALKS GIVEN

Date	To Whom	By Pilot Parent	Topic

Appendix 12 c

REQUESTS FOR INFORMATION

Date	Request From	Material Requested	Material Sent	Date

Appendix 12 d

ATTENDANCE SHEET FOR TRAINING SESSIONS

Name	Date Topic	Date Topic	Date Topic	Date Topic	Date Topic	Date Topic

Appendix 13

PILOT PARENT TRAINING
October 3 - November 21

Monday, October 3, 1977
Orientation of the Pilot Parent Program - Co-Founders:
Fran Porter, Shirley Dean
Coordinator:
Patty Smith
Pilot Parents

Monday, October 10, 1977
Film, "Cry Sorrow, Cry Hope"
Psychiatrist's View of Pilot Parents - Video tape with:
Dr. Frank Menolascino,
Associate Director of NPI

Monday, October 17, 1977
An Overview of Autism - Joe and Ginny Friend
A Look at the Boys Town Institute - Mike Weiss
Child Find of Nebraska - Cy Leise

Monday, October 24, 1977
Normalization - "A Walk Through PASS" - Tom Miller, Executive Director of GOARC
Introduction to Operation Comfort - Ron & Kathleen Sorenson

Monday, October 31, 1977
HAPPY HALLOWEEN! Stay home with the children night.

Monday, November 7, 1977
Panel Discussion - NE Epilepsy League, Helen Schaefer, Information and Referral Officer & Mary Donlin, Public Relations
Cerebral Palsy of NE, Dick Galusha, UCP Speakers Bureau
Easter Seals Society, Mary Jo Williams, Director of Care & Treatment

Monday, November 14, 1977
Community Services - Visiting Nurses Assoc., Jane Sherratt, Nurse Specialist
Eastern Nebraska Community Office of Retardation (ENCOR), Kevin Casey, Director
Meyer Children's Rehabilitation Institute, - Dr. Cordelia Robinson, Director of Infant Stimulation Program

Monday, November 21, 1977
Wine and Cheese Party - Special Guest, Dr. Frank Menolascino

Appendix 14

Pilot Parents: Educational Materials Used in Training Sessions

Pilot Parents

Pilot Parent Training Session Schedule, GOARC, 3212 Dodge, Omaha, NE 68131
Pilot Parent Brochure, GOARC, 3212 Dodge, Omaha, NE 68131
The GOARC Pilot Parent Program, GOARC, 3212 Dodge, Omaha, NE 68131
"Needs of Parents of Mentally Retarded Children"
    by Mrs. Max A. Murray, available from NARC, 2709 Ave. E East, P.O. Box 6109, Arlington, Texas 76011
"The Three Stages in the Growth of a Parent of a Mentally Retarded Child"
    by Dan Boyd, available from NARC
"The Parents of Retarded Children Speak for Themselves"
    by Charlotte H. Waskowitz, available from NARC
New Directions For Parents of Persons Who Are Retarded,
    by Robert and Martha Perske, paperback, Abingdon Press, $1.95 available at GOARC, 3212 Dodge, Omaha, NE 68131
Film: "Cry Sorrow, Cry Hope" by Penn. ARC

Mental Retardation

"Into the Light of Learning" by NARC
"NARC: A Philosophy in Action" by NARC
Nebraska ARC Brochure, NebARC, 3100 N. 14, Lincoln, NE 68508
GOARC Brochure

Epilepsy

"Because You Are My Friend", Epilepsy Foundation of America, available by Nebraska Epilepsy League, 7171 Mercy Road, Omaha, NE 68106
"Answers to the most frequent questions people ask about Epilepsy", Epilepsy Foundation of America, available by Nebraska Epilepsy League
"An Inside Look...", Epilepsy Foundation of America, courtesy Medical Clinic Pharmacy, Palo Alto, Calif.
"Facts and Figures", available by Nebraska Epilepsy League
"Medical and Social Management of the Epilipsies", available from Nebraska Epilepsy League

Cerebral Palsy

"Cerebral Palsy Hope Through Research", U.S. Department of Health, Education and Welfare, Washington, D.C.
"What is Cerebral Palsy", United Cerebral Palsy Associations, Inc., United Cerebral Palsy Association, 66 East 34th, New York, N.Y. 10016
"Cerebral Palsy, What you should know about it", available from United Cerebral Palsy, 4665 Leavenworth, Omaha, NE 68106
"Cerebral Palsy - Facts and Figures", United Cerebral Palsy Associations, Inc.

Easter Seal

Easter Seal's Camp Kiwanis, Nebraska Easter Seal Society, 12177 Pacific, P.O. Box 14204, West Omaha Station, Omaha, NE 68114
"Once Upon A Bicycle", National Easter Seal Society
"Toward a Better Life", National Easter Seal Society

Appendix 14

Normalization

- New Directions for Parents of Persons Who Are Retarded by Robert Perke, paperback, Abingdon Press, $1.95
- "Dehumanization vs. Dignity" by Minnesota Department of Public Welfare, Reprinted by NARC
- "Dignity of Risk and the Mentally Retarded" by Robert Perske, available from NARC

Community Services

- ENCOR
- Visiting Nurse Association Brochure, Division of Public Health Nursing, Omaha-Douglas County Health Department, 1201 S. 42nd Omaha, NE 68105, or from GOARC, 3212 Dodge, Omaha, NE 68131
- Meyer Children's Rehabilitation Institute Brochure
- Infant Stimulation Program, Meyer Children's Rehabilitation Institute
- Service Index of community services available to mentally retarded people
- Packet of educational materals for new parents
- Evaluation of Pilot Parent Training

Pilot Parents: Educational Materials for New Parents

Information for Families about Mental Retardation

"On Being A Parent...of a handicapped child" by Benjamin Spock, M.D., available from National Easter Seal Society for Crippled Children and Adults, 2023 West Ogden Avenue, Chicago, Illinois 60612

"Siblings of the Retarded" by Schreiber and Feeley, available from National Assoc. for Retarded Citizens, 2709 Avenue E East, Arlington, Texas 76011

"Mental Retardation" by Siegried A. Centerwall, M.D. and Willard R. Centerwall, M.D., available from Department of Pediatrics, School of Medicine, Loma Linda University, Loma Linda, California 92354

"Primer for Parents of a Mentally Retarded Child" by Elizabeth M. Stabler, available from National Assoc. for Retarded Citizens, 2709 Avenue E East, Arlington, Texas 76011

"Into the Light of Learning" by National Assoc. for Retarded Citizens, available from NARC, 2709 Avenue E East, Arlington, Texas 76011

"Your Down's Syndrome Child" by David Pitt, M.D., available from National Assoc. for Retarded Citizens, 2709 Avenue E East, Arlington, Texas 76011

"Needs of Parents of Mentally Retarded Children" by Mrs. Max A. Murray, available from National Assoc. for Retarded Citizens, 2709 Avenue E East, Arlington, Texas 76011

Epilepsy

"Because you are My Friend," Epilepsy Foundation of America, available by Nebraska Epilepsy League, 7171 Mercy Road, Omaha, NE 68106

"Answers to the most frequent questions people ask about epilepsy," Epilepsy Foundation of America, available from Nebraska Epilepsy League

"An Inside Look", Epilepsy Foundaton of America, courtesy Medical Clinic Pharmacy, Palo Alto, Calif., available Nebraska Epilepsy League

"Facts and Figures," available by Nebraska Epilepsy League
"Medical and Social Management of the Epilepsies," available from Nebraska Epilepsy League, 7171 Mercy Road, Omaha, NE 68106

Cerebral Palsy

"Cerebral Palsy Hope Through Research," U.S. Department of Health, Education and Welfare
"What is Cerebral Palsy," United Cerebral Palsy Association, Inc.
"Cerebral Palsy what you should know about it," available from United Cerebral Palsy, 4665 Leavenworth, Omaha, NE 68106
"Cerebral Palsy - Facts and Figures," United Cerebral Palsy Assoc., Inc.

Easter Seal

Easter Seal's Camp Kiwanis, Nebraska Easter Seal Society
"Once Upon A Bicycle," National Easter Seal Society
"Toward a Better Life," National Easter Seal Society

Developmental Tips

"Toilet Training Your Retarded Child" by Molly C. Corelick, Ed. D., available from National Assoc. for Retarded Citizens, 2709 Avenue E. East, Arlington, Texas 76011

"A Helpful Guide in the Training of a Mentally Retarded Child" by Virginia State Department of Health Bureau of Child Health, available from National Association for Retarded Citizens, 2709 Avenue E East, Arlington, Texas 76011

"Make the Most of Your Baby" by June Mather, available from National Association for Retarded Citizens, 2709 Avenue E East, Arlington, Texas 76011

Some Services

"School Comes Home" by Greater Omaha Association for Retarded Citizens, available also from GOARC, 3212 Dodge, Omaha, Ne 68131

"GOARC Lending Library" by GOARC, GOARC, 3212 Dodge, Omaha, NE 68131

"Eastern Nebraska Community Office of Retardation" by ENCOR, 885 So. 72nd St., Omaha, NE 68114

Parent Group Activities

The GOARC Gazette, by GOARC, available from GOARC, 3212 Dodge, Omaha, NE 68131

"What Is This ENCOR/GOARC Partnership?" by GOARC, available from GOARC, 3212 Dodge, Omaha, NE 68131

GOARC Brochure, by GOARC, available from GOARC, 3212 Dodge, Omaha, NE 68131

Pilot Parent Brochure, by GOARC, available from GOARC, 3212 Dodge, Omaha, NE 68131

Nebraska Epilepsy League Brochure, available from the Epilepsy League, 7171 Mercy Road, Omaha, NE 68106

United Cerebral Palsy Application, available from United Cerebral Palsy, 4665 Leavenworth, Omaha, NE 68106

Appendix 15

PILOT PARENTS DEFINED

(First Published in the NebARC Focus, September, 1974)

1. A pilot parent is one veteran parent "being with" and "talking with" a new parent of a retarded child (Talking, showing concern, comparing notes, trading information, sharing with each other the things they are doing).

2. A pilot parent contact is not formal counseling, a clinical visiting nor formal casework.

3. A pilot parent visits with and advises another parent as only another parent can do it.

4. A pilot parent visit should be no great big deal. It should be low key, casual and friendly.

5. A pilot parent never pushes himself on another. He and/or she merely makes themselves available.

6. A pilot parent faces the fact that he or she may not be helpful. Some new parents are not ready for help. No one can make them ready.

7. A pilot parent develops a skill of waiting and being available. When the new parent is ready, the pilot parent is ready to appear.

8. A pilot parent never lets himself become obnoxious. He or she becomes sensitive and understanding of how much a new parent can take.

9. A pilot parent is regular in his or her contacts. Not too many. Not too few.

10. A pilot parent uses the right media at the right time, (i.e., brief visit, longer visit, brief phone call, longer phone call, according to the needs and accessibility of the new parent).

11. A pilot parent does not overload the new parent with reading material. He or she finds the right piece at the right time.

12. BASICALLY, A PILOT PARENT IS ONE WHO MERELY POINTS THE WAYS THAT A NEW PARENT OF A DEVELOPMENTALLY DISABLED CHILD CAN GO UNTIL THE PARENT IS ON HIS WAY. (Like the harbor pilot who helps the captain to guide his ship out of the harbor. He points out all danger spots in the harbor. When the ship moves into the open sea on course, the pilot leaves the ship.)

Appendix 16

GUIDELINES FOR PILOT PARENTS

(First Published in the NebARC Focus, September, 1974)

1. Listen to the new parents first, find out what their fears and questions are. Talk over the problems of retardation, relating your experiences with your own child.

    Point out that mental retardation is a handicapped condition resulting from many different causes, which has as its most common characteristic a slowness in learning. Retarded children have all the same physical and emotional needs of normal children, but have the additional need of special help to overcome the difficulty in learning. Often, minor physical handicaps, which add to the learning disability, may respond to treatment, resulting in an increase in functional level. For this reason, there is a real need for obtaining a detailed medical evaluation.

2. We still have much to learn about the mentally retarded. But don't build false hopes about ultimate achievements. Just say, we don't know all the answers, that is why we parents are all working with professionals to try to find as many of the answers as we can.

    The degree of retardation—impossible to determine at birth—will to a large extent determine the child's future level of growth and development. The general purpose of careful planning for the future of a retarded child through the varied services available is not to reach any one goal, but to help the individual attain his full capacities and potentials, whatever they may be.

3. Tell about the variety of community services. Not recommended for first visit.

4. Offer to discuss retardation with other members of the family as well.

    Specifically, grandparents are often most upset and concerned by the birth of a retarded child. You may be able to ease the situation by helping them to understand the problem, too.

5. Invite parents to visit your home and meet your child and family... if appropriate.

FILMS FOR PILOT PARENT PROGRAM USE

Appendix 17

Where to obtain film, "Cry Sorrow, Cry Hope" (16 mm, 58 minutes)

To buy: Pittsburgh Broadcasting Company
4802 - 5th Ave.
Pittsburgh, PA 15213

To rent: The Pilot Parent Program
3212 Dodge Street
Omaha, NE 68131
(402) 348-9220

The University of Texas at Dallas
Callier Center for Communication Disorders
1966 Inwood Road
Dallas, Texas 75235
(c/o South Central Regional Center)

Other films available:

Epilepsy
"Images of Epilepsy" (self-awareness)
3 students - (8 year old, early detention)
(13 year old, psycho motor)
(17 year old, grand mal resentment)
Available through: Nebraska Epilepsy League, Inc.
7171 Mercy Road, Suite 129
Omaha, NE 68106

Cerebral Palsy
"Something Different"
Available through: United Cerebral Palsy of Nebraska
P. 0. Box 80103
Lincoln, NE 68501
(402) 466-8302
c/o Richard Galusha (978-7394)

Developmental Disabilities
"I See You As A Person"
Available through: Easter Seal Society for Crippled Children and Adults of Nebraska
12177 Pacific
P. 0. Box 14204 - West Omaha Station
Omaha, NE 68114
(402) 333-9306

Autism
"Bobby" (16 mm)
Available through: Information and Referral Services
NSAC
306 - 31st Street
Huntington, West Virginia 25702

NORMALIZATION

Appendix 18

The principle of normalization is part of the basic philosophy of the Pilot Parent Program and is a major subject for the training program.

The following is a definition and explanation of this philosophy as can be found in the book The Principle of Normalization in Human Services, Wolf Wolfensberger, National Institute on Mental Retardation, Toronto, Canada, 1972.

Dr. Wolf Wolfensberger defines normalization as "Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible."

This principle "...implies both a process and a goal, although it does not necessarily imply a promise that a person who is being subjected to normalizing measures and processes will remain or become normal. It does imply that in as many aspects of a person's functioning as possible, the human manager will aspire to elicit and maintain behaviors and appearances that come as close to being normative as circumstances and the person's behavioral potential permit; and that great stress is placed upon the fact that some human management means will be preferable to others. Indeed, sometimes a technique of less immediate potency may be preferable to a more potent one, because the latter may reinforce the perceived deviance of the person, and may be more debilitating than normalizing in the long run."

"The normalization principle as stated is deceptively simple. Many individuals will agree to it wholeheartedly while lacking awareness of even the most immediate and major corollaries and implications. Indeed, many human managers endorse the principle readily while engaging in practices quite opposed to it—without being aware of this discordance until the implications are spelled out. Then a manager may find himself in a very painful dilemma, endorsing simultaneously a principle, as well as practices opposed to it." Some of the major corrollaries and implications of the normalization principle are elaborated in the table below.

NORMALIZATION **Appendix 18**

Normalizaton means. . . A normal rhythm of the day. You get out of bed in the morning, even if you are profoundly retarded and physically handicapped; you get dressed, and leave the house for school or work, you don't stay home, in the morning you anticipate events, in the evening you think back on what you have accomplished; the day is not a monotonous 24 hours with every minute endless.

You eat at normal times of the day and in a normal fashion; not just with a spoon, unless you are an infant; not in bed, but at a table; not early in the afternoon for the convenience of the staff.

Normalizaton means. . . A normal rhythm of the week. You live in one place, go to work in another, and participate in leisure activities in yet another. You anticipate leisure activities on weekends, and look forward to getting back to school or work on Monday.

Normalization means. . . A normal rhythm of the year. A vacation to break the routines of the year. Seasonal changes bring with them a variety of types of food, work, cultural events, sports, leisure activities. Just think...we thrive on these seasonal changes!

Normalization means. . . Normal developmental experiences of the new life cycles.

In childhood, children, but not adults, go to summer camps. In adolescence, one is interested in grooming, hairstyles, music, boyfriends, and girlfriends. In adulthood, life is filled with work and responsibilities. In old age, one has memories to look back on, and can enjoy the wisdom of experience.

Normalization means. . . Having a range of choices, wishes, and desires respected and considered. Adults have the freedom to decide where they would like to live, what kind of job they would like to have, and can best perform. Whether they would prefer to go bowling with a group, instead of staying home to watch television.

Normalization means. . . Living in a world made of two sexes. Children and adults both develop relationships with members of the opposite sex. Teenagers become interested in having boyfriends and girlfriends, and adults may fall in love, and decide to marry.

Normalization means. . . The right to normal economic standards. All of us have basic financial privileges, and responsibilities. Are able to take advantage of compensatory economic security means, such as child allowances, old age pensions and minimum wage regulations. We should have money to decide how to spend; on person luxuries, or necessities.

Normalization means. . . Living in normal housing in a normal neighborhood. Not in a large facility with 20, 60 or 100 other people because you are retarded, and not isolated from the rest of the community. Normal locations and normal size homes will give residents better opportunities for successful integration with their communities.

Bengt Nirje

NORMALIZATION (continued) Appendix 18

Levels of action	Dimensions of action	
	Interaction	Interpretation
Primary and intermediate social systems	Eliciting, shaping, and maintaining normative skills and habits in persons by working indirectly through their primary and intermediate social systems, such as family, classroom, school, work setting, service agency, and neighborhood	Shaping, presenting, and interpreting intermediate social systems surrounding a person or consisting of target persons so that these systems, as well as the persons in them, and perceived as culturally normative as possible
Societal systems	Eliciting, shaping, and maintaining normative behavior in persons by appropriate shaping of large societal social systems, and structures such as entire school systems, laws, and government	Shaping cultural values attitudes, and stereotypes so as to elicit maximal feasible cultural acceptance of differences

Appendix 19

PILOT PARENTS PROGRAM ®

This is to Certify that

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ARE

PILOT PARENTS

THIS____________________DAY OF____________________

IN THE YEAR OF NINETEEN HUNDRED AND____________________

A Program of

GREATER OMAHA ASSOCIATION FOR RETARDED CITIZENS

____
President

____
Executive Director

PARENTS HELPING PARENTS OF HANDICAPPED CHILDREN