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THE UNIVERSITY OF KANSAS



Beach Center on
Families and Disability

Parent to Parent Information Packet



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Parent to Parent Information Packet

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1990

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INTRODUCTION

The Parent to Parent National Survey Project at the Beach Center on Families and Disability at The University of Kansas is conducting a national survey of parent support programs that use the Parent to Parent model of providing support to families who have a family member with a disability. Parent to Parent programs match an experienced or "veteran" parent of a family member with a disability in a one-to-one relationship with a new or "referred" parent who is just beginning to meet the challenges of a disability within the family. Through the match, the veteran parent is often able to provide the referred parent with the unique emotional and informational support that comes from shared experiences.

After the results of our survey of program administrators, veteran parents, and referred parents are compiled and analyzed, they will be used to develop several products for families and professionals. The following resources will be available from the Beach Center on Families and Disability by the end of the project in the fall of 1991:

- a comprehensive summary of all survey results
- a national resource directory of Parent to Parent programs
- a manual on best practices in Parent to Parent program development
- the training materials to accompany the manual on best practices
- an annotated bibliography of the literature and of available Parent to Parent program-developed materials

In response to the many requests for information on Parent to Parent program development received by the Beach Center on Families and Disability, the Parent to Parent National Survey Project has developed the Parent to Parent Information Packet. The Parent to Parent Information Packet is a collection of information and resources for Parent to Parent program

development that will be available on an interim basis until the final products listed above are developed.

There are three sections in the Parent to Parent Information Packet:

- Section 1--The Parent to Parent Model
- Section 2--Guidelines for Starting a Parent to Parent Program
- Section 3--Parent to Parent Resources

Section 1

The Parent to Parent Model

The Parent to Parent Model of providing support to parents who have a family member with a disability is a systematic approach of matching experienced or "veteran" parents of a family member with a disability with new or "referred" parents who are just beginning to meet the challenges of a disability within the family. Through this one-to-one match, the veteran parent is often able to provide the referred parents with meaningful emotional and informational support. Because veteran parents have "been there" and experienced the many intense emotional responses that accompany a disability in the family and have adjusted to and come to understand the disability, they are in a unique position to establish a meaningful bond with referred parents.

For most parents of children with special needs, the early period following the diagnosis is a time of emotional crisis. Parents may feel overwhelmed, guilty, angry, and/or depressed. Because well-meaning relatives and friends are sometimes afraid to reach out, many parents of a child with a disability also report feeling an enormous sense of isolation. For these parents then, the weeks and months following the diagnosis are ones in which the parents are often left alone, caught in a vicious cycle of disbelief, anger, depression, and fear of what the future holds for their family.

Transition times are also often stressful ones for families who have a family member with a disability. Moving from an early intervention program into an early childhood special education program, or transitioning into the public school system or a supported living/employment setting brings a whole new set of unknowns to the family. The opportunity to be matched with and talk with a veteran parent who has already experienced similar transitions may provide the family with the emotional and informational support needed to

smooth the way for everyone.

Many parents who experience this crisis of adjustment to the diagnosis, and many parents who are navigating their way through these periods of transition, can be helped in a unique way by other veteran parents who have already weathered these same life experiences. Because veteran parents are intimately familiar with the emotions and real challenges that often come with having a family member with special needs, they can offer something that other support systems cannot--shared common experiences.

New or referred parents are referred to a Parent to Parent program through a variety of sources: medical personnel, social service practitioners, disability organizations, other parents. Only after a referred parent has indicated that s(he) is interested in talking with a veteran parent, does a Parent to Parent program contact the referred parents to talk about a possible one-to-one match.

The one-to-one match between a referred parent and a veteran parent is usually determined by similarities in disability and family experiences, as well as the ability of the veteran parent to contact the referred parent within a day or two of the request for a match. Once the initial meeting between the veteran parent and the referred parent occurs, the on-going relationship develops according to the needs and preferences of the referred parent. Some matches are short-term consisting of only 2-3 contacts, others evolve into lifelong friendships. Regardless of how the relationship develops, the match with a veteran parent provides the referred parent with an opportunity to see others who have raised a child with a disability and who have accepted the child as he or she is.

Because Parent to Parent programs facilitate one-to-one matches between veteran parents who through their empathetic, sensitive, and skillful

listening offer friendship and shared experiences to the referred parents, the Parent to Parent approach is a truly viable one that is easily adaptable in a variety of settings. Families of infants in neonatal intensive care units find the same quality of support through a Parent to Parent match as do families with young adults making the transition from special education settings to supported employment or families coping with the challenges of caring for a head-injury survivor. Through any Parent to Parent match, opportunities are created for a very unique sharing of information and emotional support, and these shared experiences are the very foundation of Parent to Parent support.

The Parent to Parent Model originated formally in 1971 as the foundation for the Pilot Parents Program in Omaha, Nebraska. The development and operation of the Pilot Parents Program was handled primarily by volunteer parents, and the program quickly established itself as an effective means of helping parents to deal more successfully with the challenges that often accompany caring for a child with a disability. The Pilot Parents program expanded throughout the state of Nebraska, and the model subsequently has been replicated nationwide.

Characteristics of Parent to Parent Programs

1. Parent to Parent programs range in size from very small programs (2-3 veteran parents serving 2-3 referred parents) that are entirely organized and operated by volunteer parents to large state-wide programs (300 veteran parents serving 300 referred parents) that are staffed by parents and professionals and coordinate the efforts of several local Parent to Parent chapters. Data from the Parent to Parent National Survey Project indicate that of the Parent to Parent programs responding to the survey, 32% are small (serving fewer than 12 referred parents),

46% are medium-sized (serving 12-75 referred parents) and 22% are large (serving more than 75 referred parents).

2. Some Parent to Parent programs have the sponsorship of another organization (e.g. Association for Retarded Citizens); some do not. Some programs provide support to families dealing with only one common disability, but most Parent to Parent programs are cross-disability. Generally, families participating in the Parent to Parent network have a young child with a disability, although Parent to Parent programs that serve families with an older family member with a disability do exist.
3. Referrals to Parent to Parent programs come from a variety of sources: medical personnel, social service agencies, educational programs, friends, relatives. Once a referral is received, the referred parent is contacted by the program and invited to participate in a match. Only after the referred parent has given permission to be matched does a veteran parent initiate further contacts.
4. Matches between veteran and referred parents are established by the Parent to Parent program. Careful consideration of each family's situation is used to determine an appropriate match, including factors such as the nature of the disability, age of parents and child, family size, structure, and lifestyle, language spoken at home, and geographic location.
5. Contacts between veteran parents and referred parents are either by telephone or in person or both depending upon individual needs and preferences. The number and frequency of contacts are also determined by the veteran and referred parents themselves, as is the duration of the match.
6. The type of support provided by the Parent to Parent program to referred

parents is wide-ranging and often includes sensitive listening and mutual problem solving; information about the disability, day-to-day survival skills, and accessing community resources and services; training in advocacy skills; and group support and social activities for families.

7. Veteran parents also may receive services from the Parent to Parent program including formal training in effective strategies for serving as a resource parent; consultation and support from the Parent to Parent program staff; group support and social activities for families; and opportunities to train other parents and professionals about the challenge of a disability in the family.
8. In some Parent to Parent programs in addition to the services available for veteran and referred parents, similar support is also available for the family member with a disability and other family members.

Section 2

Guidelines for Starting a Parent to Parent Program

Starting a Parent to Parent program begins with a commitment to the value of parents supporting other parents, and to the idea of the one-to-one match between a veteran parent and a referred parent. Strengthened by these commitments, one person can successfully start a new Parent to Parent program by taking the following considerations into account:

- deciding about sponsorship/agency support
- considering funding options
- determining leadership
- learning the specifics about Parent to Parent
- informing local service providers
- recruiting and training veteran parents
- establishing the referral system,
- implementing the match

Deciding About Sponsorship/Agency Support

A Parent to Parent program may be established as an entirely volunteer organization, or it may be sponsored by a service provider agency, disability organization, or existing parent group. Data from the Parent to Parent National Survey Project indicate that 52% of the responding Parent to Parent programs are sponsored, and 48% are not. Whether to seek sponsorship is an important early decision, and the advantages and disadvantages of both a sponsored and a nonsponsored status need to be considered carefully.

A. Volunteer Parent to Parent Program with No Agency Sponsorship

1. Many Parent to Parent programs prefer the autonomy that a non-sponsored status permits. Decisions about program philosophy, components, growth and development are entirely up to the program, and program "ownership"

resides completely with the program organizers.

2. Without a formal relationship with a sponsor, volunteer Parent to Parent programs may find it useful to obtain the support of a local professional as a resource. Often a professional will have helpful contacts in the community to help the program achieve the necessary visibility to survive; or the professional can develop/implement the training sessions for the veteran parents.
3. Meeting/office space may be donated by banks, churches, and libraries.
4. Many resource materials are available free from the U.S. Government Printing Office in Washington, D.C., and from state and national disability organizations.
5. Funding efforts for non-sponsored Parent to Parent programs may be more time consuming. Data from the Parent to Parent National Survey Project indicate that 68% and 56% of non-sponsored programs receive funding from private donations and fundraising activities respectively; while 28% and 23% of sponsored programs receive funding from private donations and fundraising activities respectively.

B. Parent to Parent Program with Agency Sponsorship

1. There are many different agencies and organizations that may be interested in sponsoring a Parent to Parent program. Data from the Parent to Parent National Survey Project indicate that of the responding Parent to Parent programs, 30% are sponsored by ARCs, 22% by other social service agencies (e.g. Easter Seals, mental health centers, March of Dimes), 12% by a specific disability organization (e.g. United Cerebral Palsy, Epilepsy Association, Head Injury Foundation), 10% by neonatal intensive care units in hospitals, 9% by a statewide Parent to Parent organization, and

6% by school districts and/or special education cooperatives.

2. While sponsorship does reduce a program's opportunities for complete autonomy, a sponsoring agency because of its contact persons and visibility to the public may be able to offer a variety of resources:

- donated meeting/office space and office equipment to maintain records and coordinate the program
- underwriting of start-up and initial operating costs
- availability of professional staff for consultation as resource persons and for training of parent volunteers
- assistance with public awareness and referrals
- a not-for-profit status of an established agency to qualify for funding
- assistance with fundraising and grant writing
- a Parent to Parent telephone line for receiving referrals

Funding Considerations

Parent to Parent programs can be operated on a totally volunteer basis with little or no funding, with the force behind a program's success being the dedication and commitment of a core group of veteran parents. Data from the Parent to Parent National Survey Project show that 39% of responding Parent to Parent programs have a program budget of less than \$1000 per year, and another 19% of the programs report yearly budgets of between \$1000 and \$4999.

If a Parent to Parent program is sponsored by a local parent group or organization, some financial support may be available for start-up tasks and office space and supplies. If a Parent to Parent coordinator is employed to oversee the development and operation of the program, then often additional funds must be obtained. Possible sources for additional funding include:

- local, state, and federal grants

- private foundations and local philanthropists
- the statewide Parent to Parent organization, if one exists
- university affiliates
- specific disability organizations
- creative fundraising efforts (e.g. bake sales, trike-a-thons, silent auctions) staged by parents themselves

Determining Leadership

A Parent to Parent program may be established by any number of people--a parent of a child with a disability, a core group of parents of children with special needs, a staff member of a service provider agency, and/or a combination of parents and professionals working together. Regardless of sponsorship status, leadership roles will need to be determined.

In a sponsored Parent to Parent program often a program staff person (who may also be a parent of a child with a disability) will assume a leadership role in the development of the program. Just as critical to the success of a sponsored Parent to Parent program, however, is the involvement of the parents themselves in the organization and operation of the program. Parent involvement and strong parent commitment to the program are important factors in establishing the program's credibility with other professionals in the community, and especially with other parents. Thus an important first step for the agency staff member who takes on the leadership role in the development of the program will be to seek a core group of parents to join in the effort. Parents may want to take lead responsibility for such tasks as publicity, social events, community education, and fundraising.

In a newly developing program without sponsorship, generally a core group of parents forms a steering committee and takes the initiative for the many start-up issues. Several different subcommittees may evolve out of this

initial core group:

- chairperson to arrange for and conduct all meetings, recruit and train prospective veteran parents, organize and maintain the recordkeeping system for the operation of the program, serve as liaison between the steering committee and the community
- publicity to coordinate all community relations and public relations efforts
- assignment to coordinate all referrals and matches
- social events to organize all social events for parents and families
- fundraising to plan and coordinate the implementation of all fundraising activities
- resources to review and select resource materials for the program and for families

Getting Started

Once the program leadership and the relationship with a sponsoring agency have been defined, there are several other tasks that need to be accomplished before the recruitment and training of veteran parents can begin.

A. Learn the Specifics about Parent to Parent

1. There are many excellent information and training materials on Parent to Parent program development and implementation available from established Parent to Parent programs. See Section 3, Parent to Parent Resources and/or contact the Parent to Parent National Survey Project at the Beach Center on Families and Disability at The University of Kansas at (913) 864-7600 for further information.

B. Inform Local Service Providers

1. Sharing information about the Parent to Parent program with local service providers who will be the sources of parent referrals is

another important step. Awareness of the Parent to Parent program by the general public, parents meeting the challenges of disability within their families, and professionals within the community service system is a critical element in the success of the program.

2. There are many effective ways to promote a Parent to Parent program, and many different targets for these promotional efforts. Data from the Parent to Parent National Survey Project reveal that 96% of the responding programs use person-to-person contacts to spread the word about their program; 85% use printed materials; and 55% use the public media.
3. Word of mouth efforts and person to person sharing of information about the program by the participating parents themselves can be extremely effective ways of generating interest and support for the program. Many parents in the program may be comfortable making informal and formal presentations about the program to community groups. Shared family stories and personal testimonials about the value of the Parent to Parent program will greatly enhance the program's credibility in the community.
4. Brochures describing the program and providing a telephone number can be placed in doctors' offices, social service agencies, churches, and hospitals. Large eye-catching posters displayed in libraries, schools, businesses, and other public buildings are another way of alerting the public to the existence of the program. Many programs also send letters describing the program and information packets on specific disabilities to local physicians and the Obstetrics and Pediatrics departments of hospitals.
5. Local television and radio stations are usually very receptive to public

service announcements about community groups and thus can be helpful in publicizing a Parent to Parent program. Some communities also have their own cable television networks specifically for promoting different programs within the community. Parents from the program who are willing to appear on a local radio or television talk shows demonstrate the importance of the Parent to Parent program simply by sharing their own family story with a wider audience.

Many programs have developed their own slide-tape or videotape presentations describing the program. This format, when accompanied by parents who are actively participating in the program can be a dramatic and effective way of explaining the program to various public audiences.

Recruiting and Training Veteran Parents

One of the earliest and most important tasks in actually implementing a Parent to Parent program is the recruitment of potential veteran parents.

1. Ask the sponsoring agency and/or other community agencies providing services to children with disabilities to assist in the location of prospective veteran parents. Confidentiality usually prohibits these agencies from releasing parents' names, but agency personnel will often forward information about the program on to their parents.
2. Start small and gradually increase the number of active veteran parents to insure that quality training and support are available.
3. Work to include a diversified group of veteran parents (mothers and fathers) with representation from different disability areas, socio-economic groups, family structures, cultural and ethnic backgrounds, all of whom are willing to participate in the training sessions and are committed to the concept of parents helping other parents.
4. Hold an introductory meeting for prospective veteran parents to explain

the Parent to Parent program orientation and discuss plans for training.

5. Screen prospective veteran parents in terms of their:
- acceptance of their own child and adjustment to their family situation
 - ability to reach out and provide support to other parents
 - ability to cope with other people's problems and a tolerance of values and feelings that may be different from their own
 - willingness to share their own family story with others
 - communication skills
 - maturity and empathy
 - time available

Some programs use a screening interview and checklist to determine a parent's readiness to be a veteran parent. In other programs, a recommendation from another community agency is deemed to be sufficient. In either case, some sort of screening process will enable a program to develop a strong core group of veteran parents who are ready and eager to offer their support to others.

The training sessions for veteran parents are a critical component in a Parent to Parent program, and it is important to the overall success of the program that the training be well-planned and well-implemented. 78% of the Parent to Parent programs responding to the Parent to Parent National Survey Project indicated that their programs have a formal training program for veteran parents in place.

By participating in a quality training program, veteran parents come away with not only a solid foundation of information about disabilities and available community resources, but also some applicable skills in communication and empathetic listening. Moreover, through a comprehensive training program, veteran parents are also provided with opportunities for

self-evaluation and a time to look closely at their own values, beliefs, and actions. Strong communication skills, a solid knowledge base about disabilities and community resources, and a firm sense of self and respect for others are all essential characteristics of a veteran parent.

The format of the training and the size of the group will all vary from community to community. Generally training is provided to groups of 12-15 parents, as this group size is small enough to foster comradeship and intimacy, but large enough to stimulate the sharing of diverse backgrounds and ideas. Some helpful strategies to consider as the training program is designed are:

1. Consider the numbers of sessions, dates and locations. Some programs offer several 1-3 hour sessions over a several week period, while others develop a more concentrated program consisting of 1 or 2 full-day sessions. The time and location of the training sessions should fit the preferences of the group members.
2. Offer childcare and refreshments to make it easier and more enjoyable for the participants to attend the sessions.
3. Consider the use of local community resource persons as speakers. Many professionals are often happy to talk with a Parent to Parent group if the subject is within their area of knowledge.
4. Include content from the following topic areas:
 - orientation to the Parent to Parent program
 - positive philosophy about persons with disabilities
 - self-awareness activities
 - information about disability organizations
 - information about community resources and the referral process
 - information about financial assistance

-
- communication and listening skills
 - information about initial reactions and adjustments to the diagnosis

There are many excellent training materials for veteran parents that have been developed by Parent to Parent programs across the country. In many instances, these training guides provide all of the content, suggested resources and audio-visual materials, sample handouts, and suggested group and individual training activities for the total sequence of training sessions. Data from the Parent to Parent National Survey Project indicate that 58% of the responding programs have program-developed training materials for veteran parents, and many of these programs are able to disseminate their materials to others. See Section 3, Parent to Parent Resources, for a partial listing, and/or contact the Parent to Parent National Survey Project at the Beach Center on Families and Disability at The University of Kansas at (913) 864-7600 for further information.

5. Plan a "graduation" party to honor the new veteran parents, and award certificates to all who complete the training. A graduation party not only recognizes the "graduates", but also provides one more opportunity for the new veteran parents to bond with each other--parent to parent.

Establish the Referral System

Once community visibility for the program is obtained, and veteran parents are trained and ready to be matched, a system for handling referrals needs to be established. In the beginning, referrals are apt to come from friends, relatives, other parents, and community service providers. As the program becomes better known, potential referral sources will expand to include teachers, medical and hospital personnel, religious leaders, universities, and state agencies. Data from the Parent to Parent National

Survey Project indicate that most Parent to Parent programs receive referrals from several different sources:

- 81% of the responding programs receive referrals from medical personnel
- 77% of the responding programs listed early intervention programs as a source of referrals
- 69% of the programs mentioned friends and relatives as referral sources
- 68% receive referrals from social service agencies
- 61% get referrals from schools and/or local education agencies

Some important logistics to consider when establishing the referral system are:

1. An important first step is to select a local referral telephone number for publication and widespread distribution to all potential referral sources. Be sure to list the number in the Yellow Pages of the telephone book as well. Ideally this telephone number will be a 24 hour a day, 7 days a week number. If in Parent to Parent programs that are sponsored by another agency, this telephone number is one which can be answered by using the name of the Parent to Parent program as opposed to the name of the agency, this sort of introduction may be more comfortable for parents. Use of an answering machine, while not ideal, is preferable to having a call receive no response at all.
2. Appoint a person to coordinate incoming referrals and establish matches. This person should, if possible, be a parent of a family member with a disability. As the program grows, incoming referrals may need the attention of several members of a referral committee. The person accepting the referral confirms that the new parent is familiar with the Parent to Parent program and wishes to be matched with a veteran parent. No anonymous referrals are accepted, and no matches are made without the

expressed consent of the referred parent.

Implementing the Match

Matching a referred parent with a veteran parent is the very heart of Parent to Parent programs, and the success of the match determines the quality of support the referred parent receives from the Parent to Parent program. Thus it is important to implement matches with careful thought and planning.

1. In order for the referral coordinator or committee to determine the most appropriate match for a referred parent, it will be important to collect a minimum of descriptive information about each participating family. Parent to Parent programs participating in the Parent to Parent National Survey Project indicate that they use an average of 6 different factors to determine an appropriate match. Factors that are used by greater than 50% of the responding programs include:

- the family members with a disability have a similar disability (93%)
- the families face similar medical, educational, legal problems (90%)
- the family members with a disability are about the same age (61%)
- the families speak the same language (51%)
- the families have similar family structures (50%)

Generally, the more the veteran parent and the referred parent have in common, the easier it is for them to relate to each other. In some instances, (e.g. a very rare disability, parents who live in isolated rural areas) it may not be possible to achieve a very close match. Yet even in these cases, a veteran parent can still be very helpful and supportive to the referred parent simply by being an understanding listener and giving guidance and emotional support.

2. A system of recordkeeping will need to be implemented for keeping track of all of the information required for matching parents, as well as for

maintaining detailed records of all referrals, matches, and follow-up activities. Many programs use notebooks, or file folders for each match; a few programs use a computer to store this information and to suggest appropriate matches. Regardless of the method, an orderly, easily accessible system of recordkeeping is essential for the establishment of successful matches.

3. Once an appropriate match is determined, the veteran parent is notified and given all of the pertinent information about the referred parent. The veteran parent then contacts the referred parent, usually by telephone initially, and preferably within 24 hours of the time the referral first came in to the program.
4. Follow-up contacts occur based upon the needs of the referred parent, and the mutual schedules of the veteran parent and the referred parent. These contacts may be by telephone or in person. Some Parent to Parent matches are short-term and consist of only a very few contacts, while others evolve into lifelong relationships.
5. There are many different kinds of supports that the veteran parent is able to offer to the referred parent through the match. A listing from the data from the Parent to Parent National Survey Project of the types of supports most often provided to referred parents through the one-to-one match with a veteran parent follows:
 - someone to listen and understand (listed by 100% of the programs)
 - information about the disability (listed by 97% of the programs)
 - information about community resources (listed by 96% of the programs)
 - referrals to other agencies (listed by 96% of the programs)
 - information about caring for the family member with a disability (listed by 92% of the programs)

- problem-solving support (listed by 88% of the programs)

Considering Additional Support Strategies

Some Parent to Parent programs primarily provide opportunities for parents to participate in a match with a veteran parent. Other Parent to Parent programs supplement the opportunities for participating in a match with a variety of other activities. The number and types of support activities offered by a Parent to Parent program often vary with the size, maturity, and agency sponsorship of the program. Add additional program components only as the program is able to manage them successfully. Some options for additional support activities include:

- on-going training and consultation support for veteran parents
- group activities for parents and/or other family members for informational/educational support
- groups activities for parents and/or other family members for social support
- advocacy and/or leadership training
- training for other professionals in the community

Section 3

PARENT TO PARENT RESOURCES

Many Parent to Parent programs across the country have developed manuals, printed information, videotapes, newsletters, training curricula for parents and practitioners, and guides for program development. The following list represents only a sampling of what is available, and the Parent to Parent National Survey Project is grateful to each listed program for their cooperation in compiling this list. The contact persons listed, or other representatives from their programs, will make every effort to respond to requests for information as their own schedules and the needs of parents within their programs permit.

Arizona

Pilot Parent Partnerships
2150 E. Highland, Suite 105
Phoenix, AZ 85016
(602) 468-3001
Betsy Trombino

Special Areas of Expertise: - Reaching and meeting the needs of minorities
- Materials in Spanish
- Parent Training Center - Parent to Parent collaboration
- State-wide Parent to Parent network

Available Materials: - Agendas and related handouts for 5 training sessions in program development. Cost: \$20.00 for the complete folder.

California

Parents Helping Parents
535 Race Street, Suite 220 San Jose, CA 95126
(408) 288-5010
Florene Poyadue

Special Areas of Expertise: - Program development and fundraising
- Education and awareness training for medical practitioners
- Reaching and meeting the needs of minorities
- Sibling programs (Therapeutic Fun)
- Special needs library and clearinghouse of information for parents and professionals
- Parent training

- Available Materials:
- Better Ways--a public relations manual. \$10.00
 - Visiting Parent Manual. \$14.00
 - Communicating with Parents of Disabled Children. \$3.00
 - Do's and Don't List for Visiting Parents. \$1.00
 - Steps to Starting Self Help. \$15.00
 - A Friend Like You, A Friend Like Me. \$2.00
 - Packets on Specific Disabilities. \$8.50 each
 - Packet on Disability in General. \$8.50

Florida

Parent to Parent of Florida
3500 E. Fletcher Avenue, Suite 225
Tampa, FL 33612
(813) 974-5001
Susan Duwa

- Special Areas of Expertise:
- Statewide Parent to Parent network
 - Planning for a national Parent to Parent conference
 - Reaching and meeting the needs of minorities

- Available Materials:
- Leaders Guide. \$20.00
 - Parent Training Materials Book. \$5.00
 - CUES, a quarterly newsletter. \$10.00 subscription

Georgia

Parent to Parent of Georgia, Inc.
2939 Flowers Road S.
Atlanta, GA 30341
(404) 451-5484
Cathy Spraetz

- Special Areas of Expertise:
- Statewide Parent to Parent network
 - Computerization strategies

The Parent to Parent National Project
UAP/University of Georgia

850 College Station Road
Athens, GA 30605
(404) 542-8970
Norm Bassett

- Special Areas of Expertise:
- This project was funded for several years as the national dissemination point for training and replication of the Parent to Parent model. While not currently funded for training and technical assistance in Parent to Parent program development, the project continues to share its materials and expertise informally.

Georgia

- Available Materials: - Parent to Parent Program Development Manual
- 10 videotape modules on Parent to Parent. \$160/set
or \$21.00 to preview for 10 days.

Iowa

Iowa Pilot Parents Inc.
Iowa Exceptional Parent Center
P.O. Box 1151
33 N. 12th Street
Ft. Dodge, IA 50501
(515) 576-5870

There are several people on staff who can respond to requests for information.

- Special Areas of Expertise: - Planning a statewide Parent to Parent conference
- Using a rural telenetwork for ongoing education opportunities for parents
- Collaborative relationships with a Parent Training Center and a statewide self-help network

- Available Materials: - Parent to Parent Training Module (available Dec. 1990)

Minnesota

Pilot Parents - Minnesota
201 Ordean Building
Duluth, MN 55802
(218) 726-4745
Lynne Frigaard

- Special Areas of Expertise: - "Generic" program serving all exceptionalities, including families with children who are gifted
- meeting the needs of rural populations
- statewide Parent to Parent network
- development of clearinghouse of resources and information for families and professionals, particularly in the area of rare disorders

- Available Materials: - Sample handouts in many different topic areas are available at no cost. A SASE is requested along with acknowledgment if the handouts are duplicated. The following list of topics is a sampling of the handouts that are available:

Minnesota

- selective sharing
- communication stoppers
- grief and the adjustment process
- tips on pilot parenting
- listening skills
- dealing with people under stress

- encouraging people to talk
- how to develop a Parent to Parent program
- a rationale for a Parent to Parent program
- a rationale for training

Nebraska
 Pilot Parents
 Greater Omaha ARC
 3610 Dodge Street
 Omaha, NE 68110
 (402) 346-5220
 Arretta Johnson

Special Areas of Expertise: - As one of the first formally organized Parent to Parent programs, the staff has many years of experience and still benefits from the contacts maintained with Pilot Parents co-founders Fran Porter and Shirley Dean, and Patty McGill Smith.

Available Materials: - Pilot Parents Manual: A Design for Developing a Program for Parents of Handicapped Children. \$10.50

New Mexico
 Parents Reaching Out
 1127 University NE
 Albuquerque, NM 87102
 (505) 842-9045
 Sally Vancuren
 Debra Garcia

Special Areas of Expertise: - Collaborative relationship with Parent Training Center
 - Reaching and meeting the needs of minorities
 - Statewide Parent to Parent network
 - Parents of Preterm Infant Network

New Mexico
 Available Materials: - Parents as Case Managers Manual. \$15.00
 - Parents as Case Managers Manual for Early Childhood. \$15.00
 - Parent to Parent Support Network Manual. \$20.00
 - Training of Medical Professionals Manual. \$15.00
 - Parents of Preterm Infants Network Manual. \$10.00
 - 2 videotapes: "A Cry for Help" and "Parent to Parent Networker" \$35.00 each
 - Bi-monthly Newsletter (PRO-GRAM) - \$10.00 subscription

North Carolina

Family Support Network of North Carolina
CB# 7340, Trailer 31
University of North Carolina
Chapel Hill, NC 27599-7340
(919) 966-2841
Lynn Blanchard

Special Areas of Expertise: - Statewide Parent to Parent network
- Unique relationship between state program and local chapters, with funding and technical assistance support available
- Central directory of resources
- Promotion of parent-professional collaboration

Available Materials: - Parent to Parent Support in North Carolina--The Manual for Program Development. \$6.25
- Parent to Parent Support: Establishing a Program for Parents of Medically Fragile Children. \$6.25
- Parent to Parent Support in North Carolina--A Support Parent Reader. \$6.25
- Parent to Parent videotape. \$7.50 purchase or free loan
- Central Directory of Resources (a computerized database of 14,000 organizations, programs, services and information - call (919) 966-2841 outside NC; 1-800-TLC-0042 in NC)
- Quarterly newsletter, the UPDATE

Ohio

Family First
360 S. 3rd Street, Suite 101
Columbus, OH 43215
(614) 342-1519
Leah Holden

Special Areas of Expertise: - Statewide network

Ohio

Available Materials: - Family First Parent Curriculum Trainers Guide. \$10.00
- Family First Parent Curriculum Self-Instructional Guide

Vermont

Parent to Parent of Vermont
1 Main Street
69 Champlain Mill
Winooski, VT 05404
(802) 655-5290
Nancy DiVenere

Special Areas of Expertise: - Statewide Parent to Parent network
- Collaborative relationship with state Health Department and Handicapped Children's Services

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- Medical Education Project
 - Personnel preparation in early intervention at the University of Vermont

Available Materials: - Parent to Parent Videotape (for review and return, based upon availability)

Virginia

Parent to Parent of Virginia
Virginia Institute for Developmental Disabilities
Virginia Commonwealth University
301 West Franklin Street, Box 3020
Richmond, VA 23284-3020
(804) 225-3875 or 1-800-344-0012 in Virginia
Mary Cunningham
Bonnie Atwood
Irene Carney

Special Areas of Expertise: - Statewide Parent to Parent network

Available Materials: - Parent to Parent Training Manual. \$17.50
- Several training components
- Videotape: "Families Talk About Their Own Experiences with Disability and Parent to Parent". \$55.00
- Newsletter: In Our Shoes

Washington

Parent to Parent Support Program
2230 8th Avenue
Seattle, WA 98121
(206) 461-7834
Elaine Schab-Bragg

Available Materials: - Parent to Parent Support Coordinators Manual. \$15.00
- Parent to Parent Support Helping Parents Guide. \$7.00



**Beach Center on
Families and Disability**

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