

Section III

Developing and Expanding a Statewide Parent to Parent Program

2000

Table of Contents for Section III

Recruiting and Training Veteran Parents	23
Statewide Parent to Parent Program Stories: Recruiting, Screening, and Training	
Veteran Parents	30
Establish the Referral System and Informing Service Providers/Referral Sources	32
Implementing the Match and Providing Follow-Up Support	34
Statewide Parent to Parent Program Stories: Implementing the Match and Providing	
Follow-Up Support	38
Considering Additional Program Activities.....	41
Providing Technical Assistance to Local Programs.....	45
Building Collaborative Partnerships Statewide	47

Recruiting and Training Veteran Parents

How centralized or de-centralized a statewide Parent to Parent program is will determine how veteran parents are recruited and trained and who manages these important program activities. Results from the survey of statewide Parent to Parent program directors indicate that in 71% of the statewide programs, statewide staff offer the veteran parent training, regional staff provide the training in 28% of the statewide programs, and in 44% of the statewide programs, local program coordinators provide the veteran parent training.

In a centralized program such as Parent to Parent of Vermont, recruitment and training of veteran parents throughout the state is accomplished by the statewide program itself. Parent to Parent of Georgia, a less centralized program, relies on both statewide staff and regional staff to provide the veteran parent training. In a more de-centralized program, such as the Family Support Network of NC, each local program recruits and trains its own core of veteran parents. Most statewide programs encourage the local programs to do their own recruiting and training of veteran parents, but statewide program staff are usually available to carry out these activities if needed. Thus, depending on how centralized or de-centralized the statewide Parent to Parent program is recruitment and training of veteran parents will either be accomplished at the state level or implemented and/or supported at the local level. At either level, there are several different strategies to consider when recruiting and training veteran parents strategies that a centralized program may want to incorporate itself or strategies that a de-centralized program may want to encourage and support its local programs to adopt:

- In the early developing stages of a statewide program, it is understandable that you may want to build a base of trained veteran parents as quickly as possible, however, experienced Parent to Parent program directors recommend starting with a small number of veteran parents. Beginning slowly will allow you to ensure that quality training and support are available to each veteran parent, and that your program has the capacity to give each match the follow-up support it may need. Starting small, and gradually increasing the number of active veteran parents as you are able to do so will enable you to maintain quality.
- Think about how you will find prospective veteran parents and who might assist you in the recruitment process. If your statewide program (or local programs in your state) has a sponsoring agency, the sponsoring agency and/or other community agencies providing services to children with disabilities may be able 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 a Parent to Parent program activity on to their parents. All that you would need to do would be to supply the agency with information that they might include in their newsletter, or prepare a mailing in sealed and stamped envelopes and request that the agency attach the address labels of the families. In the newsletter article or in the mailed information, be sure to include information that tells the parents how to let you know about their interest in becoming a supporting parent and how to request additional information. Once interested parents contact you and voluntarily share their name and address, then you can begin to communicate with them directly and will no longer need the assistance of another agency.

- Work to include a diversified group of veteran parents (mothers and fathers) with representation from different disability areas, socioeconomic 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. The more diverse your core of veteran parents is, the greater capacity your program will have for matching parents around similar family and disability needs.
- Some Parent to Parent programs hold an introductory meeting for prospective veteran parents to explain the Parent to Parent program orientation and discuss plans for training. Other programs meet and/or talk individually with parents who have expressed an interest in becoming veteran parents. Either way, it is important for parents to have a chance to learn more about the role of the veteran parent, the training, and the match, before they decide whether or not to take the training. Similarly, it is important for the program coordinator to meet prospective veteran parents and to learn more about why they are interested in becoming a veteran parent and where they are in their own family lives.
- Whether through a group meeting, or an individual conversation, or as a part of the supporting parent training itself, most Parent to Parent programs **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. A copy of a screening form is included in Appendix D. 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, whether this activity occurs at the state level or at the local level.

All 100% of the statewide programs responding to the survey indicated training for supporting parents is offered in their state.

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** varies from state to state and community to community, with the content of the training being shared in a variety of different ways as depicted in Table 4.

Table 4: Format for Training Veteran Parents

Format	% Statewide Programs Reporting
Train parents in small groups	94%
Train parents individually in person	50%
Train parents individually by phone	39%
Send written training materials	28%
Send training videotape	0%
<i>Programs could circle more than one response, so %'s add up to > 100%.</i>	

Generally training is provided to groups of 8-12 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:

- Decide who will provide the training sessions. Will training be done at the local level by local coordinators, will training be conducted by regional and/or statewide program staff on behalf of the local efforts, or will training be offered locally, regionally, and statewide? Data from the survey of statewide program directors indicate that 71% of the statewide programs offer veteran parent training at the state level, in 44% of the statewide programs, local program coordinators carry out their own training, and 28% of the statewide program directors indicated that training for veteran parents is available regionally.
- 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.

- Offer childcare and refreshments to make it easier and more enjoyable for the participants to attend the sessions.
- 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.
- 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.

Just as the format for the training varies by program, so does the content that statewide programs include in their training varies, but with some topics being common to most statewide programs. Table 5 on the next page lists the major content areas of training for veteran parents and indicates what percentage of statewide programs include each respective content area.

Table 5: Content Areas of Training for Veteran Parents

Content Area	% of Statewide Programs Reporting
Overview of Parent to Parent	94%
Role of the veteran parent	94%
Emotional responses to the disability experience	94%
Communication and listening skills	94%
Making the first contact	94%
Knowing when to refer a parent for other support	89%
Problem solving skills	83%
Community resources/services	78%
Communicating with professionals	78%
Cultural diversity issues	72%
Self-care and wellness	61%
Family-centered care guidelines	61%
Values clarification	61%
Stress management	56%
Information about disabilities	50%
Parenting tips	44%
Developing advocacy skills	44%

Educational and legal rights	39%
Developing leadership skills	39%
Meeting financial realities	33%
Public speaking skills	28%

When asked which of these content areas are most important, statewide directors mentioned the role of the veteran parent and communication and listening skills with the greatest frequency.

There are many excellent training materials for veteran parents that have been developed by statewide 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 survey of statewide program directors indicate that 78% of the responding statewide programs have program-developed training materials for veteran parents, and many of these programs are able to disseminate their materials to others. See Appendix A for a partial listing, and/or contact the Parent to Parent Projects at the Beach Center on Families and Disability at The University of Kansas at (785) 864-7600 for further information. Appendix E contains sample agendas for supporting parent training.

In addition to the training for veteran parents that is provided before veteran parents are matched with another parent, statewide Parent to Parent programs often provide other supports for their veteran parents. The types of supports offered to veteran parents and the percentage of programs offering each type of support are presented in Table 6.

Table 6: Other Supports for Veteran Parents

Type of Support	% of Statewide Programs Reporting
Veteran Parent Manual	83%
1-1 Consultation	78%
Reimbursement for long distance phone calls	78%
On-Going Training	67%
Reimbursement for postage expenses	61%
Retreat/conference	56%
Support Group	44%
Reimbursement for travel expenses	44%

As is noted in Table 6, 83% of the statewide programs not only provide training for prospective veteran parents, but also have a manual that they give to veteran parents to use as a

resource beyond the training. This manual typically contains handouts related to the content of the training, a summary of the forms that the veteran parent uses to document the progress and outcome of each parent match, as well as information about community and state resources that are available to families.

After parents complete the training to serve as a veteran parent, over half of all statewide programs continue to offer six other types supports to them as they participate in their matches with other parents. Once a veteran parent begins the matched experience, there may be questions that arise around which the veteran parent might benefit from 1-1 consultation with a program coordinator. As depicted in Table 6, 78% of the statewide programs offer this 1-1 consultation at the state level; but 61% of the responding statewide program directors also indicated that 1-1 consultation was provided locally by local program coordinators, and 50% of the responding statewide directors mentioned the 1-1 consultation was available at the regional level as well. Statewide Parent to Parent programs believe not only in the importance of training parents before they begin to serve as veteran parents, but also in individualized follow-up support for veteran parents once their matches get underway.

Related to the 1-1 consultation for veteran parents that occurs after the initial round of training, 67% of the statewide programs also offer veteran parents the opportunity to participate in ongoing training sessions with other trained veteran parents. These training opportunities vary in terms of their agenda items depending upon the needs and requests of the veteran parents, but they often include time for veteran parents to brainstorm together about common issues related to their matches and to share tips with each other. Over half (56%) of the responding programs indicated that they provide a statewide conference or retreat for veteran parents – settings in which veteran parents have a chance to participate in further training and network with other veteran parents.

Statewide Parent to Parent programs acknowledge that there are sometimes expenses related to serving as a veteran parent, and because the veteran parents are volunteering their time, program coordinators make every effort to minimize any extra expenses related to the matched experience. As Table 5 indicates, statewide programs are most likely to reimburse veteran parents for long-distance telephone calls related to their match, with 78% of the programs indicating that they reimburse long distance telephone expenses. Over half of the programs (61%) reimburse for postage expenses, and close to half of the programs (44%) cover veteran parents' travel expenses related to their match.

Of all of the supports offered to veteran parents, the greatest percentage (47%) of statewide program directors indicated that the veteran parent training is the most requested by parents; a veteran parent training manual was mentioned most often (by 35%) as being the second most requested type of support, and reimbursement for expenses was identified by 29% as being the third most requested type of support for veteran parents.

The greater the number of trained veteran parents that a statewide program has available, the greater the capacity of the program will be to make a meaningful match. The data presented in Table 7 will give you an idea of how many trained veteran parents statewide programs have at

the end of the first 12 months of the program and how many trained veteran parents there are today. The number of trained veteran parents that statewide programs had at the end of their first 12 months ranges from 5650, whereas for programs today the range is from 50-2000.

Table 7: Number of Trained Veteran Parents in Statewide Programs

Number of Trained Veteran Parents	% Programs Reporting End of First 12 Months	% Programs Reporting Today
Less than 100	92%	27%
100 – 299	0%	26%
300 – 499	0%	14%
500 – 750	8%	26%
More than 750	0%	7%

Untrained Veteran Parents

While statewide programs are committed to the importance of matching trained veteran parents, occasionally and most often when a trained veteran parent is not readily found for a particular match, statewide programs will ask an untrained parent to participate in a match with a referred parent. Generally, untrained parents are parents known to a statewide program but for whom participating in veteran parent training has not been possible. While these parents have not completed the typical veteran parent training, statewide programs do provide them with an abridged version of the content that is included in the veteran training sessions. Table 8 depicts the several different methods that statewide programs use to share information with untrained veteran parents.

Table 8: Methods for Preparing Untrained Veteran Parents

Method of Preparation	% Programs Reporting
Information is provided 1-1 by telephone	89%
Information is provided by sending a manual or written materials	73%
Information is provided 1-1 in person	61%
Information is provided by sending a videotape	11%

Statewide programs typically have far fewer untrained parents than trained veteran parents available to participate in one-to-one matches, as is indicated in Table 9. Untrained parents are used only when a trained veteran parent cannot be found or when the needs of the match are unique.

Table 9: Number of Untrained Veteran Parents in Statewide Programs

Number of Untrained Veteran Parents	% Programs Reporting End of First 12 Months	% Programs Reporting Today
0 - 50	82%	49%
51 - 100	9%	7%
101 - 200	0%	7%
201 - 300	9%	7%
301 - 400	0%	7%
More than 400	0%	21%

Statewide Parent to Parent Program Stories: Recruiting, Screening, and Training Veteran Parents

Parent to Parent of Connecticut has a 9 hour training module that is available to local program coordinators, and many local chapters have adapted this training to meet the specific needs of the volunteer parents they are training. Individual local programs currently schedule and conduct their own training sessions, with support from the state office as needed. However, as Parent to Parent of Connecticut moves toward a more centralized model, the statewide office will begin to provide the training quarterly in various locations across the state.

In the past two years, **Parent to Parent of Georgia** has condensed their training for supporting parents and has increased the number of training options available to supporting parents. Statewide and/or regional staff offer a 4-hour *traditional* training for prospective supporting parents in communities who request it. But Parent to Parent of Georgia staff also recognize that many parents have training opportunities outside of Parent to Parent of Georgia, so program staff also use a personal interview or telephone interview to orient parents who may not need or cannot attend the more traditional training.

In Massachusetts, the **Family Ties Project** has developed a one day training for supporting parents that emphasizes understanding feelings, listening skills, and confidentiality. These trainings are conducting regionally and are also offered to other organizations interested in beginning their own Parent to Parent programs.

New Jersey Statewide Parent to Parent dedicates itself to having all Support Parents attend an Orientation before they are matched. Between 8-10 parents attend the 6-hour Orientation, either in one session or two 3-hour session presented within one week of each other. The Orientation provides skill-building activities around communication and listening and a time of sharing. Each Support Parent receives a manual that also becomes their log book for contacts with referred parents.

The **Family Support Network of North Carolina (FSN-NC)** offers training resources to the local programs in NC, but each local program is responsible for organize and carry out its own training for supporting parents. Some local program use the training materials developed by FSN-NC, while others adapt these materials or develop their own. Among the local programs in NC, supporting parent training typically consists of 6-8 hours of training covering such topics as the role of the supporting parent, the adjustment process, communication and listening, community resources, and role plays and simulations around contacts with referred parents.

In Pennsylvania, all new Peer Supporters receive a *Peer Supporter Manual* from **Parent to Parent of Pennsylvania** which they are encouraged to read. Peer Supporters are asked to return a self-addressed stamped postcard stating that they have read and understand the manual. Once Peer Supporters have read the manual, then they are encouraged to attend a Peer Supporter training session in their area. The full-day Peer Supporter training session is based upon the *Peer Supporter Manual* but in an expanded format. Topics include communication and listening skills, cultural diversity, confidentiality, and sensitivity. Each of the regional coordinators in Pennsylvania has training materials and suggestions for training Peer Supporters in their own regional coordinator manual. Regional coordinators may actually conduct the training, or they may arrange for local or statewide presenters to do the training.

The **Family Connection of South Carolina** offers a 12-hour Support Parent Training program that is co-facilitated by veteran Support Parents with assistance from community professionals who volunteer their time. Support Parent Training is offered at the statewide offices in Columbia and Greenville through two 6-hour training sessions held on Saturdays two weeks apart. Once Support Parents are trained, statewide staff support them through follow-up calls, opportunities to meet with other parents for social activities and mutual support, and a yearly conference. Additionally the Family Connection contracts with the SC Department of Health and Environmental Control/BabyNet (the state's early intervention program) to provide additional training to Support Parents so that they might serve as paid *Family Partners* mentoring parents of infants and toddlers with special needs. Recently the Family Connection has offered yet another training opportunity to Support Parents who wish to serve as *Resource Parents* and support parents who are considering managed care options for their children with disabilities.

Parent to Parent of Vermont statewide staff provide regionally-scheduled 8-hour Skill Building Workshops to train their Supporting Parents. Content of these workshops includes a time for sharing family stories and experiences, the adjustment process, communication and listening, tips for contacts, and the principles of family-centered care. A Facilitator's Guide and a Training Manual are available for purchase.

Training for Helping Parent volunteers in **Washington State Parent to Parent Support Programs** is the responsibility of each local Parent to Parent program, and the statewide office has a trainer available to assist local programs when requested to do so. Currently 12 of the 25 local programs in Washington conduct their own Helping Parent trainings, with the statewide office trainer conducting these training sessions for the other local programs. Local programs are encouraged to carry out Helping Parent trainings at least annually, although the number and frequency of Helping Parent training sessions varies according to local needs. Typically Helping

Parent training ranges from 10-18 hours in length, and all programs offer follow-up/ongoing training opportunities for Helping Parents.

Establish the Referral System and Informing Service Providers/Referral Sources

While efforts are underway to train supporting parents, newly developing statewide programs also work to develop a system for handling the referrals that will come in from a variety of sources. In the early weeks and months of a newly formed statewide program, referrals often come from friends, relatives, other parents, and supportive community service providers. As the statewide program becomes better known, potential referral sources usually expand to include teachers, medical and hospital personnel, religious leaders, universities, and state agencies. Table 10 presents data from the Parent to Parent National Survey Project about the sources of referrals for local and statewide Parent to Parent programs.

Table 10: Referral Sources to Parent to Parent Programs

Referral Source	% Parent to Parent Programs Reporting
Medical personnel	88%
Friends or relatives	83%
Social service agencies	83%
Early Intervention staff	76%
Schools/local education agencies	61%

As presented in Table 10, Parent to Parent programs report receiving referrals from a variety of sources, with medical personnel (physicians, nurses, hospital social workers), being mentioned by the greatest percentage of program directors. Based on these data, as you plan your outreach efforts, you will want to be sure that your program is widely promoted, and perhaps especially to the medical community. Parent to Parent programs rely on number of different strategies for building strong program visibility.

- Data from the Parent to Parent National Survey Project reveal that 98% of the responding programs use person-to-person contacts to spread the word about their program; 91% use printed materials; and 68% use the public media. Moreover, 72% of all statewide programs have a program newsletter that shares information about the program with parents and providers.
- 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.

- Brochures describing the program and providing a telephone number can be placed in doctors' offices, social service agencies, churches, and hospitals. Nearly all statewide programs (94%) report having a statewide program brochure. In states with a de-centralized statewide program, the local programs often have their own program brochures that list both a local contact number as well as the number for the statewide program. In states with centralized statewide programs, the statewide program develops one brochure for use throughout the state. As you work to develop a program brochure for your statewide program, you may find it helpful to request copies of brochures used in other states. 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. Appendix F contains some sample brochures from statewide Parent to Parent programs.
- A newsletter that describes the mission and activities of a statewide program is another effective way of publicizing your message, and 78% of statewide programs report having a program newsletter that goes out to parents and professionals. Through the newsletter you can chronicle program events and family stories to give readers a fuller understanding of the range of services that your program provides through and beyond the match. Other statewide programs will be happy to share copies of their newsletter with you so that you can collect ideas for your own.
- Some statewide programs (28%) 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.
- 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. While only 6% of statewide programs report having developed public service announcements for use in the local media, this strategy does have the potential for reaching large numbers of people.

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. Statewide program directors characterize their public relations activities as among their most important and their most challenging responsibilities. Without strong program visibility and a clear sense of the nature of the support that is provided by Parent to Parent, referrals will simply not come into the program. And because there is a relatively high turn-over of staff within the medical and social services

professions, awareness efforts must remain a priority activity of a Parent to Parent program even if the program is a mature one with a history in the community.

As the word gets out about your Parent to Parent program, you will want to be sure not only that you have trained supporting parents who are ready to be matched, but also an efficient system for taking referrals. Some important logistics to consider when establishing the referral system are:

- An important first step is to select a referral telephone number for publication and widespread distribution to all potential referral sources statewide. If funding permits, this referral number should be a toll-free 800 number so that connections to the program can be made at no expense to the caller. Ideally this telephone number will be one that is responded to in some fashion 24 hours a day, 7 days a week. Use of voice mail or an answering machine, while not ideal, is preferable to having a call receive no response at all. In a statewide Parent to Parent program that is sponsored by another agency, if this telephone number can be answered by using the name of the statewide Parent to Parent program as opposed to the name of the agency, this sort of introduction may be more comfortable for parents.
- 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.
- In a centralized statewide program, the statewide office will handle all of the referrals, whereas in a more de-centralized statewide program, responding to referrals will be the responsibility of local and/or regional program coordinators.

Implementing the Match And Providing Follow-Up Support

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 that matches are implemented with careful thought and planning – whether the matches are made by local or regional coordinators, and/or by the statewide office. Statewide program directors responding to the survey indicated that in their states matches were made locally, regionally, and/or statewide as presented in Table 11. In 50% of the responding programs, parent matches are made at more than one level.

Table 11: Level at Which Matches are Made

Level At Which Matches Are Made	% Parent to Parent Programs Reporting
Statewide	71%
Regional	65%
Local	41%

In order for the local, regional, or statewide referral coordinator 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. Local and statewide 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 responding programs are presented in Table 12 on the next page.

Table 12: Factors Used in Making Matches

Factor Used	% Parent to Parent Programs Reporting
Family members with a disability have a similar disability	96%
Families face similar medical, educational, legal problems	91%
Family members with a disability are about the same age	57%
Families live close by	49%
Families have similar family structures	47%
Families are of similar cultural/ethnic background	40%
Parents are about the same age	36%
Parents have similar education and income	32%

The parent-researcher team that conducted the efficacy study of Parent to Parent (See Appendix G for additional information about the Parent to Parent Efficacy Study and its results), learned from interviews with referred parents who participated in the study that aside from the factors listed in Table 12, the quality of the parent match is enhanced if several other factors are considered as well. Referred parents in the study who were most satisfied with their matches reported that their supporting parent had:

- Similar personality characteristics to their own
- A similar philosophy about parenting
- A similar communication style to their own
- Similar attitudes about disability and expectations for their child with a disability

These individual and personal characteristics and styles may be more difficult for Parent to Parent program staff to be aware of than such other factors as disability of the child, but the research suggests that they are equally important to consider when making parent matches. One important way for Parent to Parent program staff to get to know each veteran parent is by bringing prospective veteran parents together for training. As parents who wish to be veteran parents spend time sharing their own family stories and experiences with each other, program staff have an opportunity to get to know them in a more personal way. This personal knowledge can then be used to make the best possible matches.

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 for a local program to achieve a very close match. Most (61%) statewide programs maintain a computerized database of veteran parents available across the state, and thus often are able to find a statewide match when a local effort is not successful.

A system of record keeping 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; more statewide programs use a computer to store this information and to suggest appropriate matches. Regardless of the method, an orderly, easily accessible system of record keeping is essential for the establishment of successful matches. Appendix H contains some sample forms for documentation of the match and its progress.

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.

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. Recently completed research on the efficacy of the one-to-one parent match indicates that referred parent satisfaction with the match increases with the number of contacts from the veteran parent – and that veteran parents should strive for a minimum of four contacts during the first eight weeks of the match. See Appendix G for a summary of the results of this research.

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 appears in Table 13.

Table 13: Supports Provided to Referred Parents

Supports Provided Through Match	% Programs Reporting
Someone to listen and understand	100%
Information about the disability	98%
Information about community resources	96%
Information about caring for the family member with a disability	96%
Referrals to other agencies	95%
Problem-solving support	93%

Follow-Up Support for the Match

The research results from the efficacy study of Parent to Parent support suggest that referred parent satisfaction with the matched experience depends in part on the factors upon which the match is made and on the number of contacts the referred parent receives from the veteran parent. In order to ensure that contacts between the veteran parent and the referred parent are happening, and that the match is as good a fit in reality as it is on paper, program coordinators are working to improve the follow-up support that each match receives. Many program coordinators, local, regional, or statewide are now contacting the veteran parent within 2-3 days after they have been matched with a referred parent just to be sure that the important first contact has been made and to answer any questions that the veteran parent may have. Similarly, program coordinators often contact the referred parent during this same time period to see how the match is progressing and feeling to them. Additional contacts between the program coordinator and both parents also occur, especially during the first few weeks of the match. Moreover, both the veteran parent and the referred parent are informed that, despite the great care with which matches are made, not all matches are just right for all parents, and that a re-match can be made at any time for any reason.

Samples of logs for documenting the contacts and the progress of each match, as well as of reminder postcards that are used by many programs to ensure that at least four contacts occur during the first eight weeks of the match can be found in Appendix H.

Statewide Parent to Parent Program Stories: Implementing the Match and Providing Follow-Up Support

RAISING Special Kids in Arizona has a computerized database of its families and volunteer support parents, giving the organization a more systematic means of matching parents on issues of interest to them. Using this same computerized system allows for more efficient documentation of follow-up support for each match.

In the last 12 months, **Parent to Parent of Connecticut** has made approximately 350 matches statewide, with each documented on a standardized technical assistance form. With the shift toward a more centralized organizational model, greater success has been achieved in collecting and documenting information about both referred and veteran parents and in using a computerized system for matching parents.

Parent to Parent of Georgia uses a comprehensive tri-part database to support both its parent matching program and the information and referral program. The first part of the database is the peer database. The peer database holds all of the demographic and descriptive information about supporting parents who are available to be matched. The second part of the database holds information about referred parents – information that is useful in matching referred parents with supporting parents and also for sharing information with referred parents about resources. The third part of the database is the provider database, and it holds information on all resources that are available to families (currently there are over 10,000 resources in the provider database. A file server stores all of the information in all three databases, and each computer in state and regional offices is connected to the file server through a local area network. Parent to Parent of Georgia matches parents based on disability and any other specifics requested by the referred parent. Once a match is made, both the supporting parent and the referred parent receive correspondence from the statewide office about the specifics of the match, and both parents are encouraged to contact the state office if the match does not work out. Follow-up efforts happen as staff time allow with efforts being made so that this follow-up is not viewed as intrusive.

Parents who would like to be matched with a support parent contact the **Family Support Network of Michigan** either by completing a self-addressed stamped postcard which is part of the FSN promotional brochure, or by phone. The statewide office forwards the request to the local FSN coordinator in the parent's geographical area. Local FSN coordinators are committed to contacting referred parents within 24 hours of receiving an request for support. After talking with the referred parent about the kinds of issues they would like to be matched around, the local FSN coordinator finds an appropriate match. The number of matches made and the hours required for completion of the matches are documented by local FSN coordinators in their quarterly reports to the statewide program.

For **Parent to Parent of New Hampshire**, the statewide coordinator responds to all referrals to the program. Using an in-take form, the statewide coordinator gathers the relevant demographic and disability information for use in making the match, and then searches a statewide database of 688 supporting families and 116 trained supporting parents. Once a match is made, the statewide coordinator reinforces this connection by contacting both the referred and

the supporting parent within two weeks of the match. Parent to Parent of New Hampshire now uses a system of four reminder postcards to encourage supporting parents to make at least four contacts during first eight weeks of the match.

Parents seeking support can contact **New Jersey Statewide Parent to Parent** by sending in the response form within the program brochure, or by calling the 800 number. When a call is received on the 800 number, the statewide coordinator talks with the parent about the kind of match they are seeking and gathers information about their child with special needs and their family. The statewide coordinator searches the statewide database for a support parent living close to the referred parent. Then the statewide coordinator passes the parent's name and contact information, as well as that of the supporting parent to the appropriate Regional Associate. The Regional Associate monitors the first four contacts between the support parent and the referred parent and encourages the support parent to complete these four contacts within the first two months of the match. The support parent returns a post card to the Regional Associate after each of these first four contacts. If either parent is not completely satisfied with the match, the Regional Associate is a resource to both parents and will make another match for the referred parent if necessary. At the end of the first two months of each match, a questionnaire is sent to the referred parent to (1) ensure that all has gone well, (2) find out if an additional match would be helpful, and (3) encourage the referred parent to consider becoming a support parent.

Parents Reaching Out in New Mexico has matched approximately 150 families in the last year for information and support, with referrals coming from early childhood programs, school districts, Medicaid Managed Care providers, health care providers, hospitals, and social service agencies. All parent matches are documented from the time of referral on data sheets sorted by computer. To facilitate matching requests, family profile is developed for both referred parents and for supporting parents. Once matches are made, all parents, referred and supporting, receive follow-up contacts by either letter or phone.

Referrals to **Parent to Parent of New York** come from new parents, parents of newly diagnosed children, or professionals working with families. The regional or statewide coordinator first speaks with the referred parent to learn more about any preferences for a match; and then presents the match opportunity to a potential supporting parent with similar family and disability issues. Once a match is made, both parents receive contact information about each other. The regional or statewide coordinator calls the support parent two weeks after the match was made, and again at the end of the first three months of the match to learn more about the progress of the match and to collect data about the number of contacts and whether additional information or resources are needed. In the last 12 months, Parent to Parent of New York provided 1100 parents with the opportunity to be matched with a support parent and shared information either individually or in a group setting with 7,613 parents/professionals. Requests for matching by e-mail now average 1 to 2 per day.

In North Carolina, through the **Family Support Network of North Carolina**, parent matches are primarily made by coordinators of local Parent to Parent programs across the state. Each local program determines the specific procedures for matching parents and each local program is responsible for the follow-up of their own matches. When a match is requested in an

area that does not have a local Parent to Parent program or if a local program cannot find a support parent for a match, the statewide office searches its statewide database to find an appropriate match. Within the last 12 months, 1,294 referred parents in North Carolina were matched with supporting parents

Family Connection of South Carolina Program Coordinators (four full-time and two part-time) seek to match parents by the expressed need of the parent, and find that most often matches are made around similar disability issues. A goal of the Family Connection is to match referred parents within 24 hours of the referral, and for the referred parent and Support Parent to have spoken within 48 hours. Once matches are made, Program Coordinators follow up with the referred parent and/or the Support Parent to ensure that the match meets the needs of the referred parent and the Support Parent. Program Coordinators encourage Support Parents to make a minimum of four contacts with referred parents and send Support Parents a letter reminding them of the importance of these contacts. As the match gets underway, Program Coordinators make additional calls to the Support Parent to provide ongoing support.

Family Connection of SC has expanded its capacity to do parent matching by contracting with the SC Department of Health and Environmental Control/BabyNet, the state's early intervention program to direct the Family Partners program. Parents who are already trained as Support Parents receive additional training in early intervention issues, and then are paid to serve as Family Partners and be matched with parents of infants and toddlers with disabilities. Since 1992, when the Family Partners program began, Family Partners have provided more than 55,000 hours of information and support to over 2,500 families. In a similar adaptation, several Support Parents were selected to participate in additional training so that they can be matched with and provide information and support to parents who are considering managed care options for their children with special health care needs.

Washington State Parent to Parent Support Program has an 800 number for responding to referrals and requests for information, and each autonomous local program has its own program number for local contacts. The statewide program provides callers with information about services that are available statewide and connects them with the local program nearest to them. Each local program is responsible for providing services to families from their area of the state (typically county-wide) and maintaining records and follow-up with the families. Once a referral is received at the local level, the local program coordinator is responsible for making contact with potential Helping Parents in their area, assessing their availability, making, supervising, and providing follow-up support to the match, and communicating with the referral sources about the services the referred parent is receiving. Because all of the local programs as well as the statewide program are connected through a computerized network, if a local program does not have the information a caller is seeking, or cannot make a local match, the local program coordinator can contact other local programs and the statewide program via e-mail for assistance.

Considering Additional Program Activities

Some statewide 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 statewide Parent to Parent program often vary with the size, maturity, and agency sponsorship of the program, as well as the interests of parents involved with the program. These other program activities may be activities that are geared especially for family members, or they may be activities that the program offers to professionals. Experienced statewide Parent to Parent program directors recommend adding additional program components only as the program is able to manage them successfully.

Program Activities for Family Members

As a statewide Parent to Parent program begins to match parents for information and support, many participating parents express an interest in other types of support as well. Program activities for families above and beyond the match supplement and enhance the matched experiences for many parents involved in a statewide Parent to Parent program. Table 14 presents information about the type of program activity offered for family members and to what extent this program activity is coordinated by local programs, regional programs, or the statewide program.

Table 14: Provision of Program Activities for Families

Program Activity	% of State Programs	% of Regional Programs	% of Local Programs
Conference	78%	6%	11%
Lending Library	78%	28%	39%
Financial Support	56%	22%	22%
Activities for Siblings	39%	11%	39%
Activities for Families	22%	17%	39%
Computer Center	17%	17%	33%
Extended Family Member Activities	17%	11%	39%
Toy Library	0%	11%	22%
Equipment Library	0%	6%	11%

The vast majority (78%) of statewide programs host a conference (usually annually) to share information and offer networking opportunities for parents. While professionals may also attend/participate in a statewide Parent to Parent conference, statewide Parent to Parent

conferences offer sessions that are designed especially for parents. Topics on the agenda often include:

- Special education rights and responsibilities
- Respite care
- Communicating with professionals
- Healthcare issues (e.g., SSI, waivers, dealing with insurance companies and HMOs)
- Stress management/humor
- Community resources
- Legislative awareness
- Tips for navigating complex educational, legal, and medical systems
- Sibling issues

Lending libraries are important resources for families who are searching for additional information about a wide variety of topics (e.g., specific disabilities, related services and equipment, the family experience). Most statewide programs (78%) offer a lending library that contains both print and video resources for parents (and/or local or regional Parent to Parent program coordinators) to borrow at no charge. As you will note in Table 14, statewide programs do not offer similar lending libraries for equipment (e.g., walkers, wheelchairs, modified furniture) and for toys – these lending libraries are instead offered by the local and regional programs around the state. Some statewide programs (17%) offer a computer center for parents and children with special needs to try out various computer equipment and software, or seek information or connect with other families on the Internet.

While statewide Parent to Parent programs do not pay for services that a child with a disability may need, they do provide a great deal of information about the availability of financial assistance and help guide families through the process of determining a child's eligibility for financial support. However, as noted in Table 14, 56% of statewide Parent to Parent programs do offer at least to some extent, financial supports through scholarships to attend conferences, and reimbursement for childcare expenses and travel costs related to participation in program activities.

Often a family's introduction to a Parent to Parent program will be through a match between one parent and a supporting parent. As the match gets underway, other family members may become interested in benefiting from the emotional and informational support that statewide programs offer through (a) group activities for whole families, (b) activities for siblings, and (c) activities for extended family members (particularly grandparents). Families who have a child

with a disability sometimes feel isolated from families who do not have a child with a disability, and family activities for offered by a statewide program can do much to reduce this sense of isolation.

As you consider other program activities to add, you may find it helpful to refer to the *Statewide Parent to Parent Gifts and Talents* list and the *Roster of Statewide Parent to Parent Programs* that appear in the Appendix A. The *Statewide Parent to Parent Gifts and Talents* listing indicates which statewide Parent to Parent programs have expertise in establishing and coordinating program activities beyond the match. The *Roster of Statewide Parent to Parent Programs* provides contact information for each statewide Parent to Parent program. Talking to the directors of statewide programs about their program activities beyond the match may give you some helpful ideas.

Program Activities for Professionals

In addition to offering program activities beyond the match for parents, many statewide programs are involving themselves in the pre-service and in-service training of professionals who will be or are already working with families who have children/adults with disabilities. Parents as trainers and community faculty bring an important perspective to service delivery that cannot be fully captured in a textbook or classroom setting. Some examples of innovative pre-service and in-service training activities that are currently being carried out by statewide Parent to Parent programs follow.

RAISING Special Kids in Arizona collaborated with Southwest Human Development Inc. (well-respected for its professional training department and its family centered style of service delivery) to form the Southwest Institute for Family Centered Practice – an innovative professional development entity. The Southwest Institute for Family Centered Practice offers a variety of **in-service training** opportunities for professionals to help them learn about, adopt, and incorporate into their work, the principles of family-centered care. At the Southwest Institute for Family Centered Practice, family members are equal partners in both the development of the training content and the training methods, and in the delivery of the training sessions as co-trainers.

The core of the Southwest Institute for Family Centered Practice training package is a five-day training experience entitled *Building Effective Relationships for Family-Centered Practice*. An intensive learning experience that requires participants to reflect on their own experiences and share those with others, *Building Effective Relationships for Family-Centered Practice* consist of six training modules:

- The Process of Change
- Self-Assessment of Beliefs, Attitudes, and Values
- Elements and Application of Family-Centered Practice
- Building Collaborative Partnerships
- Inclusion of Males in Service Delivery
- Professional Ethics and Boundaries in Family-Centered Practice

The training content can be customized to meet the unique training needs of each group of participants, and active training techniques are used throughout each module. Moreover, family members who have been consumers of services are represented in each training session to share the family perspective. At the end of the training session, participants will have an individualized plan for how they will implement family-centered care principles in their own delivery of services. Professionals pay a fee to attend the 4-5 day training session and eventually the training itself will be credentialed, and the program itself self-sustaining.

The **Family TIES** program in Massachusetts has collaborated with the Institute for Community Inclusion at Children's Hospital on a pilot project entitled *Learning Together*. Through the project, family members co-developed and co-presented **in-service training** sessions on family-centered care for health professionals. An offshoot of the *Learning Together* project has been the *Family Grand Rounds* series – a project in collaboration with the American Academy of Pediatrics. Through this project, Family TIES hosts discussion forums with local health care providers that enhance their understanding of the family perspective.

Parent to Parent of Vermont coordinates a number of different **pre-service training** opportunities for medical, education, and health professionals. In partnership with the Department of Pediatrics at the University of Vermont Medical School, the Medical Education Project provides medical students with a four-part seminar entitled *The Practice of Family-Centered Care*. The goals of the seminar are to:

- Provide medical students with an opportunity to step out of their student role and into the role of a parent of a child with special needs.
- Help medical students learn the art of practicing medicine.
- Create a learning environment that helps medical students to understand their own values and personal beliefs and how they may affect their practice of medicine.
- Give medical students a chance to see an individual with a disability in a family setting within a community.
- Increase medical student's understand of the joys and challenges of the disability experience – for the person with special needs and for their family.

All third year medical students are required to attend the four-part seminar. Parent to Parent of Vermont staff serve as co-faculty teaching the first two sessions of the seminar along side of physician faculty members at the University of Vermont Medical School. For the third part of the seminar, each medical student is matched with a family who has a child with special needs. Before their match with a medical student, each family participates in an orientation to learn more about the Medical Education Project and to consider which of their family experiences they would like to share with the medical student. The medical student and the family decide together when the medical student will visit the family. *The family experience is*

the learning experience. A final fourth session consists of a facilitated discussion to help the medical students reflect on their home visit with the family and to consider this experience within the context of the entire seminar. Students share the messages they received from the families and integrate these messages into their own personal understanding of family-centered care. Within the last 12 years, 687 medical students have had the privilege of learning from families who have opened their homes and shared their wisdom and experiences.

The success of the Medical Education Project has prompted Parent to Parent of Vermont to work in partnership with other faculty at the University of Vermont to broaden the education of those preparing to work with children and families. For the past four years, all first year graduate students in the Communication Sciences Department have been matched with families. Additionally, Parent to Parent of Vermont staff and parents have been involved as adjunct faculty for the Early Childhood Specialist Certification program at the University of Vermont. Parent to Parent of Vermont teaches seven 3-hour sessions in family-centered care over the course of an academic year. A third teaching opportunity that Parent to Parent of Vermont has is with the Vermont Interdisciplinary Leadership Education for Health Professionals Program. The goal of this program is to ensure appropriate family-centered community based training for advanced students working with children with or at risk for developmental disabilities. As a part of their training, students are matched with families for a year long family-based experience that enhances the education of the students while providing families with an ally and an advocate. Students develop their relationship with families during the first semester, and in the second semester, the students design with the family a mutually agreed upon and mutually beneficial project to be completed by the end of the semester.

Many of the other statewide Parent to Parent programs are offering pre-service and/or in-service training opportunities for service providers who are or will be serving children with special needs and their families. Please refer to the *Statewide Parent to Parent Gifts and Talents* list and the *Roster of Statewide Parent to Parent Programs* that appear in the Appendices. Talking to the directors of statewide programs about their program activities for professionals may give you some helpful ideas.

Providing Technical Assistance to Local Programs

Statewide Parent to Parent programs, and particularly those that are more decentralized and have a network of local programs, provide a wide variety of technical assistance and other supports to local Parent to Parent programs in their state. These supports to local coordinators range from training and technical assistance in program development to financial and administrative support for the maintenance of the local program. Table 15 presents information about the type of technical assistance/support offered by the statewide program for the coordinators of local and regional Parent to Parent programs in their states.

Table 15: Technical Assistance/Supports Offered by Statewide Programs for Local Program Coordinators

Type of Technical Assistance or Support	% of Statewide Programs Offering to Local Coordinators	% of Statewide Programs Offering to Regional Coordinators
A statewide program brochure or other promotional literature	56%	50%
Technical assistance in program development/ operation	56%	56%
A program development manual for program coordinators	44%	39%
Administrative office support to help with mailings	44%	28%
Group meetings with other program coordinators	39%	56%
Training to be a local/regional program coordinator	33%	44%
A resource manual with information about disabilities and community resources	33%	39%
Reimbursement for travel expenses	28%	39%
Reimbursement for telephone expenses	28%	39%
Reimbursement for postage expenses	28%	33%
Printing services	17%	39%

Over half of statewide programs (56%) produce a statewide program brochure that can be used by local/regional programs as well. The brochure often provides contact information for the statewide program itself, but then may also list local programs and their contact information as well. Or in some cases, the brochure developed by the statewide program will leave a space within the brochure for the local/regional program to affix its own relevant contact information. Appendix F provides some sample statewide program brochures. Local/regional programs often find that their own credibility and visibility efforts are enhanced when they are seen as being a part of a statewide entity.

In a similar way, 56% of statewide programs offer technical assistance in the development of a local Parent to Parent program. The format for this technical assistance varies – some statewide programs (33%) bring all new local program coordinators together for a group training session; others provide technical assistance on an as needed basis as new programs emerge. As

indicated in Table 15, 44% of statewide programs have a program development manual that is a resource to those wishing to start a local program. Once a new local program is on its way, 39% of the statewide programs provide opportunities for local program coordinators to meet with other local program coordinators to share information, best practices, and mutual support.

The Family Support Network of NC has a unique system for supporting the coordinators of new local programs in NC – a system that is modeled on the Parent to Parent match itself. As new local efforts identify themselves to the statewide office, the statewide office collects descriptive information about their newly developing program (e.g., its setting, its fiscal realities, its program development team, its priorities) and then based upon these factors, makes a program to program match with a veteran local program coordinator in NC whose program has had program development experiences similar to those being addressed by the newly developing program. The veteran local program coordinator provides individualized information and support to the new local program coordinator in a flexible and responsive way just as supporting parents do for the parents with whom they are matched.

Approximately 1/3 of the statewide programs offer **administrative and/or fiscal supports** to local/regional coordinators (e.g., office support for mailings, reimbursement for travel, telephone, postage expenses). Whether or not these administrative/fiscal supports are offered by the statewide program seems to depend upon the level of autonomy of the local/regional programs. In most statewide programs (72%), the local coordinators are not paid by the statewide program, and local program coordinators are responsible for finding funding for the administrative costs of their programs. So in these 72% of the statewide programs, the statewide program does not provide administrative fiscal supports to the local programs. However, 50% of statewide programs have paid regional coordinators on their staff, and where regional coordinators are considered to be part of the statewide staff, the statewide program is more apt to pay for administrative costs. As you will note in Table 15, statewide programs offer most of the **programmatically types of technical assistance** (e.g., training, manuals, technical assistance) to both local and regional program coordinators at about the same extent.

Please refer to the *Statewide Parent to Parent Gifts and Talents* list and the *Roster of Statewide Parent to Parent Programs* that appear in the Appendix A for more information about statewide Parent to Parent program expertise in providing technical assistance to local programs. Talking to the directors of statewide programs about their training and technical assistance activities for local/regional program coordinators may give you some helpful ideas.

Building Collaborative Partnerships Statewide

As a key player in their home state, most statewide Parent to Parent programs have established partnerships with other statewide efforts. Table 16 presents the percentage of statewide programs that have partnerships with different statewide entities in their home state.

Table 16: Collaborative Partnerships with Other State Organizations

State Organization	% of Statewide Programs in Partnership
Lead Agency – Health	94%
Part C – Early Intervention	89%
Developmental Disability Council	82%
State Disability Organization	82%
Hospital	82%
Lead Agency – Education	77%
University Affiliated Program (UAP)	77%
Lead Agency – Social Services	70%
Parent Training and Information Center (PTI)	70%
Lead Agency – Rehabilitation	59%
School Districts	50%
State Arc	47%

The nature of these partnerships varies on a continuum according to the players and the purpose of the collaboration. On one end of the continuum there are **networking partnerships** that consist primarily of the mutual sharing of information with another agency. The vast majority of statewide Parent to Parent programs have a program brochure (94%) and/or a newsletter (78%) that they share widely with parents and other agencies involved in family support as a way of networking. Statewide Parent to Parent programs also share promotional literature from other agencies with parents who are involved in Parent to Parent. Networking partnerships are easy to develop and maintain, and they are essential to a statewide Parent to Parent program’s visibility and credibility.

Partnerships may also exist as **coordinating partnerships** wherein each of the partners modifies its own agency behavior on behalf of the families it serves. For example, most statewide Parent to Parent programs enjoy a system of mutual referrals with many other local and statewide agencies. The statewide Parent to Parent program shares information about and refers parents to the partnering agency; and likewise the partnering agency informs parents about and makes referrals to the statewide Parent to Parent program. Coordinating partnerships require ongoing nurturing and particularly of those providers who are working directly with families. The staff turnover rate is high in social services professions, and in order for referrals to be easily made and received, there must be strong links between and among those who are meeting and talking with families on a daily basis.

Several statewide Parent to Parent programs have coordinating partnerships with universities and University Affiliated Programs (UAP). Parents involved with Parent to Parent of

Vermont serve as *community faculty* at the University of Vermont Medical School. These parents teach medical students in university classrooms and are also matched with medical students for meetings in the family's home. Similar opportunities exist through the University of Vermont UAP for Vermont parents to be matched with graduate students preparing for careers in early childhood special education, nursing, and occupational and physical therapy. Other statewide Parent to Parent programs (Parent to Parent of NH, Parents Reaching Out in NM, Family Support Network in NC, and the Family Connection of SC) also have coordinating partnerships with their respective medical schools to educate medical students about the family perspective.

A **cooperative partnership** exists when agencies share and work toward a common vision or purpose. For example, as noted in Table 16, 89% of statewide Parent to Parent programs are working closely with Part C Early Intervention efforts to bring early intervention services to all young children and families. Some of these statewide programs (Parent to Parent of GA, Indiana Parent Information Network, Family TIES in MA, Family Support Network of NC) also receive contracts from their state Part C program to serve as the statewide early intervention resource directory providing information and referral to parents who have infants and toddlers with developmental delays.

Moreover, the Family Connection of SC in 1992 was awarded a contract by the state to develop and implement the Family Partner program – a program that provides Parent to Parent support for parents of children who are eligible for BabyNet, the state's early intervention program. Family Partners are parents of young children with special needs who are already trained as supporting parents and who receive additional training so that they are especially prepared to support parents of infants and toddlers who are eligible for early intervention services. Since 1992, trained Family Partners have provided more than 55,000 hours of Parent to Parent support to over 2,500 families.

The Family Support Network of Michigan enjoys a cooperative partnership with (and one that also includes substantial funding from) Michigan's Title V program that is administered by Children's Special Health Care Services (CSHCS). While CSHCS provides specialty medical care to children with eligible diagnoses, until 1988, families had to live with decisions made by CSHCS and no organized way to improve the system. In 1988, CSHCS created the Parent Participation Program (PPP) to provide ideas and opinions for enhancing this system of services. From the efforts of parents involved in the work of the PPP, the Family Support Network of Michigan emerged as a source of emotional and informational support for parents who have children with disabilities and/or special health care needs. Today there are more than 50 FSN chapters offering emotional support and practical suggestions for day-to-day living, information about available services, and tips for working with others to meet family needs.

The Parent to Parent Support Program in WA also has a cooperative partnership and state contract with its Title V program. The contract to the Parent to Parent Support Program in WA came as a result Washington's response to the federal mandate to involve parents in planning, program, and policy development. The Parent to Parent Support Program and the Washington State Department of Health, Office of Children with Special Health Care Needs have established

and are modeling parent-professional collaboration and family-centered practices; and parents who participate in the Parent to Parent Support Program in WA provide parent input on a wide variety of issues, tasks, and projects being considered/implemented by the Washington State Department of Health, Office of Children with Special Health Care Needs.

Parent to Parent of VT has established multiple cooperative partnerships with several different state entities – the Title V program, Part C (early intervention), the Vermont Parent Training and Information Center (PTI), and one with the network of Parent Child Centers to develop a peer support model for **all** families.

Another level of partnership is a **collaborative partnership**. Collaborative partnerships occur when individuals or agencies are willing to enhance the capacity of others, even at the expense of some tradeoffs. An example of a collaborative partnership between a statewide Parent to Parent program and a Parent Training and Information Center (PTI) occurred several years ago in Florida. Florida had a strong PTI and a strong statewide Parent to Parent program, and yet both realized that even greater strength and capacity could be achieved by merging the two organizations. The Family Network on Disabilities of Florida emerged as the statewide organization where families can obtain both the information and advocacy support that PTIs provide and the emotional support through the one-to-one parent match that Parent to Parent programs provide. The PTI and the statewide Parent to Parent program each lost some autonomy, but families gained in that they now have a one-stop shop for services.

Several other statewide Parent to Parent programs also have close partnerships with the state Parent Training And Information Centers, and thus offer families a single point of access. The statewide Parent to Parent programs in Arizona (Raising Special Kids), California (Parents Helping Parents), Kansas (Families Together), Louisiana (Families Helping Families), New Mexico (Parents Reaching Out), Utah (Hope: A Parent to Parent Network) also serve as the Parent Training and Information Center for their state. And the Parent Training and Information Centers in New York and New Jersey each serve as the fiscal agent for the statewide Parent to Parent program. In each of these instances, the statewide Parent to Parent program and the PTI believe that the efforts of each can be enhanced and made more accessible to families through the establishment of a close partnership.

As indicated in Table 16, statewide Parent to Parent programs enjoy partnerships with a number of other statewide entities. These partnerships may be networking, coordinating, cooperative, or collaborative; but whatever the nature of the partnership, the existence of these partnerships is evidence of their importance both to the statewide Parent to Parent program and to families.

Please refer to the *Statewide Parent to Parent Gifts and Talents* list and the *Roster of Statewide Parent to Parent Programs* that appear in the Appendices for more information about statewide Parent to Parent program expertise in building partnerships with other state entities. Talking to the directors of statewide programs about their partnerships may give you some helpful ideas.

Appendix I contains a workbook/planner that summarizes many considerations that need to be addressed when starting/expanding a statewide Parent to Parent program.

Statewide Parent to Parent Resources

Many statewide 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. Appendix A provides contact information for the program and descriptive information about some of these available resource materials. The contact persons listed, or other representatives from these programs will make every effort to respond to requests for information as their own schedules and the needs of parents within their programs permit.

The Parent to Parent Project at the Beach Center on Disability is grateful to each listed program for its cooperation in compiling this list. If you are aware of other programs that might have resources to share with others, we hope that you will contact us. We are always eager to learn of new local and statewide efforts, and we welcome the opportunity to share this information with others.