

Statewide Parent-to-Parent Programs: Partners in Early Intervention

Parents of infants and young children with disabilities or special health care needs are thrust, often without warning, into an unfamiliar and complex world that requires support for and information about a whole host of medical, educational, legal, financial, social, and emotional realities. Statewide early intervention efforts have a valuable ally in statewide parent-to-parent programs in meeting the needs of families of young children with special needs. This article reports on the descriptive results of a national survey of statewide parent-to-parent programs and suggests ways in which parent-to-parent programs and early intervention efforts can support and enhance their respective efforts on behalf of young children and families. Key words: *early intervention, mentor parents, mutual support, parent support, Parent-to-Parent*

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INTRODUCTION: PARENT-TO-PARENT PROGRAMS

Parent-to-parent programs provide emotional and informational support to parents of children who have special needs. To provide this support, trained and experienced veteran parents are carefully matched in one-to-one relationships with parents who are newly referred to the program. Because the veteran parent has shared the experience of disability in the family, the veteran parent is often able to provide a unique form of support that only another parent who has "been there" can. When a referred parent of an infant or toddler is matched with a veteran parent shortly after a diagnosis is made, the veteran parent is able to act as a tour guide to the early intervention system for the referred parent. Veteran parents help new parents to interpret and understand the system and to find the best possible services for their young child with special needs.

The first formally organized parent-to-parent program, the Pilot Parents Program, was started in Omaha, NE, by a young mother of a child with Down syndrome. She worked closely with a social worker at the Greater Omaha Arc who shared her vision of a program to foster one-to-one connections between parents. The program grew rapidly, and within a few years the founders received a

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federal grant to train others to replicate the Pilot Parents model. Parent-to-parent programs began to spring up in the Midwest, fueled by the energies and commitments of parents who believed fervently in their importance. The model has since spread throughout the United States and is also prevalent in countries outside the United States, particularly in Canada, Australia, New Zealand, England, and Denmark.¹⁻⁴

In the fall of 1988, the Beach Center on Families and Disability at The University of Kansas initiated a national survey of local parent-to-parent programs to discover more about the evolution of the Pilot Parents model. Results from the survey indicate that the number of local parent-to-parent programs has grown from 1—the Pilot Parents Program at the Greater Omaha Arc in Omaha, NE, in the early 1970s—to hundreds of active local parent-to-parent programs in every region of the country. Local parent-to-parent programs range from very small ones serving just a few parents to very large ones serving several hundred families. Some are brand new programs and some have been around for 20 years. Some of these programs have no annual budget; a few have budgets of more than \$100,000. Less than half of parent-to-parent programs have a paid coordinator, and all of the veteran parents who are matched with referred parents are unpaid.⁵⁻⁷ All parent-to-parent programs provide emotional and informational support to families through the one-to-one parent-to-parent match between a veteran parent and a newly referred parent, and the vast majority of these programs are cross-disability. Today more than 600 active programs are offering services to families through the one-to-one parent-to-parent match, and more than 65,000 parents are participating in parent-to-parent programs across the nation.

Of the families participating in parent-to-parent as referred parents, 85% have a child with special needs who is younger than 12.⁷ With Part C of IDEA supporting early intervention services for infants and toddlers with disabilities, more families are being connected with parent-to-parent programs at the time of the birth of their child.

Efficacy of Parent-to-Parent Support

In response to requests from parents and program directors of parent-to-parent programs for efficacy data on parent to parent, a participatory action research team of parents and researchers conducted a 3-year national study to determine the effectiveness of parent-to-parent support for referred parents. The results of this study indicate that parent-to-parent support increases parents' acceptance of their situation and their sense of being able to cope. Moreover, parent-to-parent support helps parents to make progress on the need they present when they first contact a parent-to-parent program, and more than 80% of the parents found parent-to-parent support to be helpful. In fact, the data indicate a direct correlation between the number of contacts referred parents have with their supporting parent and how satisfied referred parents are with the support they receive—the greater the number of contacts, the greater the satisfaction.⁸ Interviews with parents suggest that the kind of support parent-to-parent programs offer is unique and cannot come from any other source.⁹

A complete listing of citation information on recent literature about parent-to-parent programs appears in Appendix A.

Statewide Parent-to-Parent Programs

In 29 states there are not only local parent-to-parent programs, but there is also a statewide parent-to-parent. Statewide parent-to-parent programs provide information and emotional support through matching across the state. They also often provide training and technical assistance to local efforts to support the development of new local programs and to nurture the growth of existing programs. In many states, the statewide parent-to-parent program also maintains a statewide database of families willing to be matched around specific disability issues, so that if a local parent match cannot be found, the parent may be able to find a match with another parent living in the same state.

In some states the statewide parent-to-parent program also serves as the parent training and

information center (PTI). PTIs are federally funded parent centers that provide training and information to parents who have children with special needs around the educational and legal rights of children with disabilities. The statewide parent-to-parent program also may have a close tie with early intervention or with a university. Statewide parent-to-parent programs sometimes evolve from existing local programs that are seeking statewide coordination and technical assistance; in other cases, the statewide parent-to-parent program comes first with local efforts following later. In some states, the statewide parent-to-parent program is centralized, with all referrals, matching, follow-up support for the matches, and training for supporting parents happening out of the state office; in other states, the statewide parent-to-parent program is decentralized and provides resources and technical assistance to a network of autonomous local programs.

Although some statewide parent-to-parent programs have been in existence for 20 years in the United States, there has been little systematic study or description of the statewide programs themselves. In response to the lack of data on statewide parent-to-parent programs, the Beach Center conducted a two-phase survey of statewide parent-to-parent programs to learn more about (a) the demographic and organizational characteristics of statewide parent-to-parent programs; (b) the program components and services that statewide parent-to-parent programs provide; and (c) the training and technical assistance statewide programs offer to local programs and parents. Between 1995 and 1996, directors of statewide parent-to-parent programs participated in Phase 1 of the survey. Between 1997 and 1998, the coordinators of the local programs in states that have a statewide parent-to-parent program participated in Phase 2 of the survey. The data collected from both surveys provide a national picture of how statewide parent-to-parent programs are operating today and offer guidelines for developing or expanding a statewide parent-to-parent program. A summary and discus-

sion of these data, as well as implications for early intervention services, are presented in this article.

METHODS

Questionnaires

Both questionnaires used in the study were developed with the close assistance of seven national leaders in a parent-to-parent program who served as members of the participatory action research (PAR) team for the project, and in accordance with many of the mail survey guidelines documented in the professional literature.¹⁰

The questionnaire for directors of statewide parent-to-parent programs consisted of 63 questions with a combination of closed- and open-ended items as well as opportunities for program administrators to rank the importance of various items within some of the questions. Questions on the survey were divided into four major categories: (a) demographic and administrative characteristics; (b) program components, supports, and services; (c) technical assistance provided to local parent-to-parent program coordinators; and (d) materials, resources, and expertise available from the program.

The questionnaire for coordinators of local parent-to-parent programs in states having a statewide parent-to-parent program consisted of 68 questions with a combination of closed- and open-ended items as well as opportunities for local coordinators to rank the importance of various items within some of the questions. Questions on the survey were divided into four major categories: (a) demographic and administrative characteristics; (b) program components, supports, and services; (c) technical assistance provided to local parent-to-parent program coordinators; and (d) satisfaction of local coordinators with the services provided to them by the statewide program.

Both questionnaires were reviewed by members of the PAR team and then field tested with statewide program administrators and local program coordinators from six different statewide parent-to-parent programs. We developed the final versions of each

survey by integrating the suggestions from our PAR team and the suggestions we received from the field test.

Procedures

The results of the national survey of local parent-to-parent programs conducted by the Beach Center yielded descriptive data about local parent-to-parent programs and also informed us about the existence of statewide parent-to-parent programs in 17 states.^{3,11,12} We advised each of the directors of these 17 statewide parent-to-parent programs that we were initiating a survey of statewide parent-to-parent programs and invited their participation. To ensure that we didn't miss any other statewide parent-to-parent programs in other states, we also mailed descriptive information about the survey of statewide parent-to-parent programs and an invitation to participate to all of the local parent-to-parent programs in the 33 remaining states. Statewide parent-to-parent program directors interested in participating in the survey returned a response form to us, indicating their willingness to complete the survey and to assist us in reaching the coordinators of local programs in their states. Collectively these efforts generated a mailing list of 21 statewide parent-to-parent programs that were interested in participating in the two-phase survey. Review of this list by key leaders in the parent-to-parent program suggested that this list was complete.

In the fall of 1995, we initiated Phase 1 of the survey by sending a packet containing (a) a cover letter explaining the survey opportunity and inviting participation; (b) the survey for statewide parent-to-parent program directors; (c) two copies of an informed consent form—one copy to be returned to us with the survey and the second to be retained by the person completing the survey; (d) a postage-paid business reply envelope for respondents to return the survey booklet and the informed consent form to us; to the 21 statewide program directors who expressed an interest in participating in the survey. Two weeks after the initial mailing, a reminder/thank you postcard was sent to all

programs. Three weeks after the first postcard was mailed, a second reminder postcard was sent to programs that had not returned a survey. Three months after the second reminder postcards were sent out, all programs that had not returned a survey received a third and final reminder postcard. Over the next 15 months, 18 (85%) of these programs returned surveys. All those returning surveys received a copy of the survey results and a complete set of one-page fact sheets on disability and family issues developed by the Beach Center.

In spring 1997, the directors of statewide parent-to-parent programs who had participated in Phase 1 of the survey assisted us by sending survey packets to the coordinators of local parent-to-parent programs in their states. Each survey packet contained (a) a cover letter explaining the survey opportunity and inviting participation; (b) the survey booklet for coordinators of local parent-to-parent programs; (c) two copies of an informed consent form—one copy to be returned to us with the survey and the second to be retained by the person completing the survey; (d) a postage-paid business reply envelope for respondents to return the survey booklet and the informed consent form to us. Two weeks after the initial mailing, statewide program directors once again assisted us by attaching mailing labels to a reminder/thank you postcard and sending the postcards to all of the local program coordinators in their states. Three weeks after the first postcard was mailed, statewide directors forwarded a second reminder postcard to local program coordinators in their states who had not returned a survey. Three months after the second reminder postcards were sent out, with the assistance of statewide program directors, all programs who had not returned a survey received a third and final reminder postcard. Over the next 12 months, 37 coordinators of local programs (25% of the 121 contacted) in 12 different states returned surveys. All those returning surveys received a copy of the survey results and a complete set of one-page fact sheets on disability and family issues developed by the Beach Center.

RESULTS

Phase 1

Demographic and Organizational Models

Demographics

The results of Phase 1 of the survey reflect the 18 statewide parent-to-parent programs responding to the survey. Table 1 provides demographic information about the 18 statewide parent-to-parent programs. Program age is determined by the year in which the program was founded. Indicators of program size are (a) the number of local programs within the statewide network, and (b) the number of trained veteran parents that are ready to be matched.

A hallmark of the parent-to-parent program is parent leadership and autonomy. Of the statewide programs responding to the survey, 67% are led by a full-time program director, and in 83% of the programs, the director is a parent of a family member with special needs. The vast majority of programs (82%) are incorporated as their own not-for-profit agency.

Table 1. Demographics of Statewide Parent-to-Parent Programs

Program Characteristics	% Programs reporting
Age of Statewide Program	
1-5 years old	35%
6-9 years old	35%
> 10 years old	30%
Number of Local Programs	
1-6	50%
7-15	31%
> 16	19%
Number of Trained Veteran Parents	
1-99	27%
100-299	26%
300-499	14%
500-750	26%
> 750	7%

Organizational Models

Although the 29 statewide parent-to-parent programs are unique in how they are organized and how they meet the needs of local efforts, there are some common organizational styles and themes. There seems to be a continuum of centralization that statewide programs vary on in terms of their structure and how they interact with parents or local programs.

Centralized model. On one end of the continuum, there are statewide programs such as Parent to Parent of Vermont that are completely centralized. Because Vermont is a small state, with all of its many small rural communities accessible by car within a few hours, coordinating all parent-to-parent activities out of the statewide office is quite manageable. All referrals come to the Parent to Parent of Vermont central office staff through a single access number. The staff at the central office maintains the roster of trained supporting parents and makes all the matches. After a match is made, the statewide program staff document the progress of the match and provide follow-up support to the match as needed.

Parent to Parent of Vermont develops all the training and promotional materials needed and used throughout the state. Brochures, public service announcements, and flyers are all produced in the central office and all have the same look and same access number for families all across the state. Local supporting parents may help to distribute these promotional materials in their communities on behalf of the statewide effort. And because most of the local communities in Vermont are small, with only one or two parents who have children with special needs, there are not enough parents in most communities to support the development of local community-based parent-to-parent programs. Parents and providers in Vermont connect to parent-to-parent services only through the statewide office.

Decentralized model. Other statewide programs are more decentralized, with the statewide

program providing training and technical assistance to local parent-to-parent programs across the state. The local programs carry out parent-to-parent activities in their communities with the statewide program assisting as requested. The Family Support Network of North Carolina (FSN-NC) is an example of a decentralized statewide parent-to-parent program with the statewide program supporting the activities of a network of 25 local programs and nurturing the development of new program efforts as they arise.

Local programs develop at their own pace in their home communities, and each local program may look very different. Each local program within FSN-NC has its own name and identity, and the programs develop on their own. The local programs in North Carolina either have their own 501(c)3 nonprofit status or they are sponsored by another nonprofit organization in the community. Some local programs have paid coordinators, some do not, and most local program coordinators are part-time and have the full responsibility for carrying out program activities. Local programs have their own local governing or advisory boards that work with the local program coordinator to raise funds and plan programs.

Each local program handles its own promotional efforts by producing its own brochures and flyers, and each local program has its own number for taking referrals. The coordinator of the local program makes the matches and also may provide the training to the supporting parents. Some of the local programs do just parent matching; others have a wide variety of other program activities.

The Family Support Network of North Carolina, as the statewide program, provides technical assistance to these autonomous local programs or chapters across the state. FSN-NC supports the local efforts but does not control the programs' development. As a resource to the local programs, FSN-NC trains local coordinators for their important role and provides technical assistance in all aspects of program operation. FSN-NC also offers training for parents wishing to be supporting parents if a local program requests that training. When a local coor-

dinator cannot find a local match, FSN-NC can search its own statewide database of parents to make a statewide match.

Somewhere in between. Most statewide parent-to-parent programs fall somewhere in between a completely centralized program and a completely decentralized program. These programs offer statewide support and services to parents or local parent-to-parent efforts and often employ regional coordinators to assist and personalize the services in their respective regions. Data from the survey of directors of statewide programs indicate that more than 75% of statewide parent-to-parent programs have at least two regional coordinators.

Funding for Statewide Parent-to-Parent Programs

Statewide parent-to-parent programs sometimes start 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 parents. However, as a statewide program becomes more established and it begins to add staff and program activities, and to encourage the development of more local programs, a more substantial funding base is necessary to support this growth. In Table 2 it is apparent that the annual program budgets of responding programs ranged from less than \$1,000 to \$500,000, both at the end of the first 12 months and today, but with some significant differences in the percentage of programs reporting in each category.

As you will note in Table 2, at the end of the first 12 months, more than 75% of the programs reported an annual budget of less than \$100,000, whereas today more than 75% of the programs report an annual budget of more than \$100,000. Clearly statewide programs have been successful in expanding the size of their initial annual budgets.

Where to find funding not only to support a newly developing statewide parent-to-parent program but also to support the program for the long term is a critical question for program leaders. Table 3 presents the funding sources that supported

Table 2. Annual Budgets of Statewide Programs: End of First 12 Months and Today

Annual budget at end of first year	End of first 12 months	Today
<\$1,000	6%	0%
\$1,000-4,999	6%	0%
\$5,000-9,999	0%	0%
\$10,000-24,999	33%	0%
\$25,000-49,999	11%	17%
\$50,000-99,999	22%	0%
\$100,000-249,999	17%	33%
\$250,000-499,999	6%	28%
>\$500,000	6%	22%

statewide parent-to-parent programs at the end of the first 12 months, and those that support their programs today.

Partnerships with Other State Entities

Statewide parent-to-parent programs enhance their capacity and their reach by collaborating with other statewide entities, and as a key player in their home state, most statewide parent-to-parent pro-

grams have established partnerships with other statewide efforts. Table 4 presents the percentage of statewide programs that have partnerships with different statewide entities in their home state.

The nature of these partnerships varies according to the players and the purpose of the collaboration. Some partnerships may consist primarily of the mutual sharing of information with other agencies. Other partnerships may be manifested by a

Table 3. Funding Sources for Statewide Programs: At End of First 12 Months and Today

Funding source	End of first 12 months	Today
State Funds:		
Developmental Disabilities Council	33%	11%
State Title V/Dept. of Health	28%	33%
State Department of Education	17%	17%
University	11%	28%
Line item on state budget	0%	11%
Federal Funds:		
Maternal and Child Health	11%	17%
Part C—Early Intervention Funding	6%	39%
Parent Training and Information Center	0%	17%
Other Funds:		
Donations	22%	33%
In-kind services	17%	17%
Private foundation grants	17%	39%
Fundraisers	11%	33%
Civic clubs	11%	17%
United Way	11%	11%
Hospitals	6%	17%
Churches	6%	17%
School districts	0%	6%

Table 4. Collaborative Partnerships with Other State Organizations

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

system of mutual referrals with many other local and statewide agencies. Still others may involve funding, contracts, and joint grantwriting efforts. As noted in Table 4, 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. The majority (77%) of statewide parent-to-parent programs has partnerships with universities and University Affiliated Programs in which parents serve as *community faculty* to educate preservice students about the family perspective.

Program Components, Supports and Services

Recruiting and training veteran parents

How centralized or decentralized 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 decentralized 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 decentralized the statewide parent-to-parent program is recruitment and training of veteran parents will either be accomplished at the state level or implemented 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 decentralized program may want to encourage and support its local programs to adopt: Information about these strategies, the content of veteran parent training, and other supports that are offered to veteran parents appears in earlier literature about parent-to-parent support.⁶

Establishing the referral system

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 5 presents data from the Parent to Parent National Survey Project about the sources of referrals for local and statewide parent-to-parent programs.⁷

Information about the strategies used by parent-to-parent programs to promote their program services to providers as potential referral sources and to parents appears in earlier literature about parent-to-parent support.⁶

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. Statewide program directors responding to the survey indicated that in their states matches were made locally, regionally, or statewide as presented in Table 6. In 50% of the responding programs, parent matches are made at more than one level.

For the local, regional, or statewide referral coordinator to determine the most appropriate match for a referred parent, he or she collects a minimum of descriptive information about each participating family. Local and statewide parent-to-parent programs participating in the Parent to

Table 5. 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%

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Table 6. Levels at Which Matches Are Made

Level at which matches are made	% Parent-to-Parent programs reporting
Statewide	71%
Regional	65%
Local	41%

Parent National Survey Project indicate that they use an average of six different factors to determine an appropriate match, considering such factors as the disability and age of child, specific issues needing to be addressed, geographic proximity, similarity in family structure.⁷ Moreover, the parent-researcher team that conducted the efficacy study of parent-to-parent programs learned from interviews with referred parents who participated in the study that aside from the factors listed above, the quality of the parent match is enhanced if several other factors are considered as well.⁹ Referred parents in the study who were most satisfied with their matches reported that their supporting parent had similar:

- personality characteristics to their own
- philosophies about parenting
- communication style to their own
- attitudes about disability and expectations for their child with a disability

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.

After 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 on 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, whereas 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.⁸ 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, many program coordinators, local, regional, or statewide are now contacting the veteran parent within 2 to 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. 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 rematch can be made at any time for any reason.

Phase 2

Technical Assistance Provided to Local Program Coordinators or Parents

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 7 presents information about the type of technical assistance

Table 7. 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 Local coordinators satisfied/very satisfied
A statewide program brochure or other promotional literature	56%	77%
Technical assistance in program development/operation	56%	52%
A program development manual for program coordinators	44%	87%
Administrative office support to help with mailings	44%	75%
Group meetings with other program coordinators	39%	56%
Training to be a local/regional program coordinator	33%	62%
A resource manual with information about disabilities and community resources	33%	74%
Reimbursement for travel expenses	28%	78%
Reimbursement for telephone expenses	28%	89%
Reimbursement for postage expenses	28%	89%

and support offered by the statewide program for the coordinators of local and regional parent-to-parent programs in their states.

More than half of statewide programs (56%) produce a statewide program brochure that can be used by local and 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.

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 7, 44% of statewide programs have a program development manual that is a resource to those wishing to start a local program. After 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. More than half of all local program coordinators reported being satisfied or very satisfied with each of the technical assistance services offered by statewide programs. Clearly statewide parent-to-parent programs are effective resources for parents wishing to develop or direct local parent-to-parent programs in their home communities.

DISCUSSION

Statewide parent-to-parent programs are an essential part of a system of comprehensive early intervention services for young children with disabilities and other special health care needs and their families. Veteran parents offer credible emotional and informational support to new parents through the one-to-one parent match, and are in a unique position to help new parents to learn about and navigate a sometimes complicated service system. Because veteran parents have *been there* themselves, they naturally employ best practices in

family-centered care, offering information and support in ways that only another parent can.

Given the nature of parent-to-parent support, it is not surprising that early interventionists are beginning to align themselves with statewide parent-to-parent programs in ways that enhance the efforts of both the parent-to-parent program and the early intervention efforts statewide. For example, because the federal government has mandated that early intervention services be family centered, and because parent-to-parent programs provide family-centered services (and often to parents who have just learned of the diagnosis of their young children), there has been an increase in the number of collaborative partnerships between early intervention efforts and parent-to-parent programs. For example, as noted in Table 4, 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. Moreover, as indicated in Table 3, six times as many statewide parent-to-parent programs receive Part C funds today (39%) as did during the first 12 months of their existence (6%).

As state early intervention programs have worked to develop the statewide early intervention resource directory to ensure that parents of young children receive relevant information and referrals, they recognize that many statewide programs already have such a database in place, not just for families receiving early intervention services but for all families who have children with special needs. 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.

Other partnerships between statewide parent-to-parent programs and statewide early intervention efforts are also emerging. The Family Connection of SC in 1992 was awarded a contract by the state of SC 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 by the Family Connection of SC as supporting parents, and who then receive additional training so that they are especially prepared to support parents of infants and toddlers who are eligible for early intervention services. In full recognition of the importance of their support to parents of young children, Family Partners are paid for their participation in parent matches. Since 1992, trained Family Partners have provided more than 55,000 hours of parent-to-parent support to more than 2,500 families of young children with disabilities in South Carolina.

As possible partnerships between early intervention initiatives and statewide parent-to-parent programs are explored, prospective partners will find it helpful to know about how the statewide parent-to-parent program is organized and how it delivers its services. If the statewide parent-to-parent program is centralized, then potential partnerships with early intervention efforts will happen at the state level as they do in Vermont. Partnerships at both the local and the state level are possible when the statewide parent-to-parent program is decentralized and local parent-to-parent programs exist across the state, as is true in North Carolina. Similarly, after it becomes clear about how referrals for parent-to-parent support occur and how matches are made in a given state, then possibilities for shared and mutually beneficial activities between parent-to-parent programs and local or state interagency coordinating councils become more easily understood. A list of the currently existing statewide parent-to-parent programs appears in Appendix B. Contact the directors of these programs to find out about local parent-to-parent programs in your state or to explore possible partnership opportunities at the local or state level on behalf of families who have infants and toddlers with special needs. Most states that do not have a statewide parent-to-parent program do have strong local parent-to-parent programs. These local programs are providing the

same kinds of supports and services to parents of children with disabilities as the statewide programs do, and they will welcome an opportunity to explore partnership opportunities with early intervention service providers at the local level.

SUMMARY

When early intervention providers are aware of the existence, nature, and the unique support opportunities that local and statewide parent-to-parent programs offer to families who have young children with disabilities or special health care needs, there are a number of ways in which partnerships between early intervention efforts and parent-to-parent programs can improve the quality of the supports and services these young children and families receive. Mutual promotional efforts and referrals will mean that the services provided by early intervention programs and parent-to-parent programs will be more visible and more accessible. Including local and statewide parent-to-parent program representatives as members of local and state interagency coordination councils will mean that parent-to-parent support is more integrated into a comprehensive system of supports for families. When families cannot find parent-to-parent support in another setting within their community, early intervention providers may want to consider partnering with parents to develop and fund a parent-to-parent program to meet the emotional and informational needs of parents whose young children are receiving early intervention services. And perhaps most importantly, parents of young children with disabilities will receive personalized, individualized emotional and informational support from another parent who has learned from personal experience about the world of early intervention services.

Further information about local and statewide parent-to-parent programs can be obtained by contacting the senior author at: The Beach Center on Families and Disability, 3111 Haworth Hall, The University of Kansas, Lawrence, KS 66045; (785) 864-7600; beach@dole.lsi.ukans.edu.

REFERENCES

1. Boukydis CF, Lester B, Hoffman J. Parenting and social support networks in families of term and preterm infants. In: Boukydis CF, ed. *Research on Support for Parents and Infants in the Postnatal Period*. Norwood, NJ: Ablex Publishing Corporation; 1987.
2. Hornby G. Launching parent to parent schemes. *Br J Spec Educ*. 1988;15(2):77-88.
3. Hornby G, Murray R, Jones R. (1987). Establishing a parent to parent service. *Child Care Health Dev*. 1987;13:277-288.
4. Iscoe L, Bordelon K. Pilot parents: Peer support for parents of handicapped children. *Child Health Care*. 1985;14(2):103-109.
5. Santelli B, Turnbull A, Marquis J, Lerner E. Parent to parent programs: Ongoing support for parents of young adults with special needs. *J Vocational Rehabil*. 1993;3(2):25-37.
6. Santelli B, Turnbull A, Lerner E, Marquis J. Parent to parent programs: A unique form of mutual support to families of persons with disabilities. In G Singer, L Powers, eds. *Families, Disability, and Empowerment: Active Coping Skills and Strategies for Family Interventions*. Baltimore: Brookes Publishing Company; 1993.
7. Santelli B, Turnbull A, Marquis J, Lerner E. Parent to parent programs: A unique form of mutual support. *Infants Young Child*. 1995;8(2):48-57.
8. Singer GHS, Marquis J, Powers L, et al. A multi-site evaluation of Parent to Parent programs for parents of children with disabilities. *J Early Intervention*. 1999;3(22):217-229.
9. Ainbinder J, Blanchard L, Singer GHS, et al. A qualitative study of Parent to Parent support for parents of children with special needs. *J Pediatr Psychol*. 1998;23:99-109.
10. Dillman DA. *Mail and Telephone Surveys: The Total Design Method*. New York: John Wiley & Sons; 1978.
11. Santelli B, Turnbull A, Higgins C. (1996). Parent to parent support and health care. *Pediatr Nurs*. 1996;23(3):303-306.
12. Santelli B, Turnbull A, Marquis J, Lerner E. Parent to parent programs: A resource for parents and professionals. *J Early Intervention*. 1997;21(1):73-83.

Appendix A

Citation Information on Recent Literature about Parent to Parent (1993–1999)

- Ainbinder, J., Blanchard, L., Singer, G.H.S., Sullivan, M., Powers, L., & Marquis, J., & Santelli, B. (1998). How parents help one another: A qualitative study of Parent to Parent self-help. *Journal of Pediatric Psychology* 23, 99-109.
- Santelli, B., Singer, G.H.S., DiVenere, N., Ginsberg, C., & Powers, L. (1998). Participatory action research: Reflections on critical incidents in a PAR project. *Journal of the Association for Persons with Severe Handicaps*, 23(3), 211–222.
- Santelli, B., Turnbull, A., Lerner, E., & Marquis, J. (1993). Parent to parent programs: A unique form of mutual support to families of persons with disabilities. In G. Singer & L. Powers (Eds.), *Families, disability, and empowerment: Active coping skills and strategies for family interventions*. Baltimore: Brookes Publishing Company.
- Santelli, B., Turnbull, A., Marquis, J., & Lerner, E. (1993). Parent to parent programs: Ongoing support for parents of young adults with special needs. *Journal of Vocational Rehabilitation*, 3(2): 25–37.
- Santelli, B., Turnbull, A., Marquis, J., & Lerner, E. (1995). Parent to parent programs: A unique form of mutual support. *Infants and Young Children*, 8(2): 48–57.
- Santelli, B., Turnbull, A., Sergeant, J., Lerner, E., & Marquis, J. (1996). Parent to parent programs: Parent preferences for support. *Infants and Young Children*, 9(1): 53–62.
- Santelli, B., Turnbull, A. & Higgins, C. (1996). Parent to Parent support and health care. *Pediatric Nursing*, 23(3): 303–306.
- Santelli, B., Turnbull, A., Marquis, J., & Lerner, E. (1997). Parent to Parent programs: A resource for parents and professionals. *Journal of Early Intervention*, 21(1): 73–83.
- Singer, G.H.S., Marquis, J., Powers, L., Blanchard, L., DiVenere, N., Santelli, B., & Sharp, M. (1999). A multi-site evaluation of Parent to Parent programs for parents of children with disabilities. *Journal of Early Intervention*, 22(3): 217–229.

Appendix B

Statewide Parent-to-Parent Programs

Arizona

Raising Special Kids
4750 Black Canyon Highway,
Suite 101

Phoenix, AZ 85017-3621
(602) 242-4366
FAX: (602) 242-4306

Arkansas

Parent to Parent
200 Main
Little Rock, AR 72206
(501) 375-7770
FAX: (501) 372-4558

California

Parents Helping Parents
3041 Olcott Street
Santa Clara, CA 95054-3222

(408) 727-5775

FAX: (408) 727-0182

Colorado

Parent to Parent of Colorado
c/o UCP of Colorado
2200 S. Jasmine Street
Denver, CO 80222

(303) 627-8888
FAX: (303) 719-2389

Connecticut

Parent to Parent Network of CT
The Family Center
282 Washington
Hartford, CT 06106
(860) 545-9021
FAX: (860) 545-9201

Florida

Family Network on Disabilities
of Florida

2735 Whitney Road
Clearwater, FL 34520
(813) 523-1130
FAX: (813) 523-8687

Georgia

Parent to Parent of Georgia
2872 Woodcock Blvd., Suite 230
Atlanta, GA 30341
(770) 451-5484
FAX: (770) 458-4091

Indiana

Indiana Parent Information Network
4755 Kingsway Drive, Suite 105
Indianapolis, IN 46205

(317) 257-8683
FAX: (317) 251-7488

Kansas

Families Together, Inc.
501 SW Jackson, Suite 400
Topeka, KS 66603
(785) 233-4777
FAX: (785) 233-4787

Kentucky

Parent Information Network of
Kentucky
PO Box 5266
Louisville, KY 40255-0266
(502) 452-9802
FAX: (502) 485-0035

Louisiana

Families Helping Families
4323 Division Street
Suite 110
Metairie, LA 70002-3179
(504) 888-9111
FAX: (504) 888-0246

Massachusetts

Family Ties—MA. Dept. of Public
Health
DCSHCN, 4th Floor
250 Washington Street
Boston, MA 02108
(617) 624-5979
FAX: (617) 624-5990

Michigan

Family Support Network of
Michigan
1200 6th Street, 3rd Floor, South
Tower, #316
Detroit, MI 48226-2495
(313) 256-2186 or (800) 359-3722
FAX: (313) 256-2605

Nevada

Nevada Parent Network—UAP
College of Education/285
Reno, NV 89557-0082
(702) 784-4921
FAX: (702) 784-4997

New Hampshire

Parent to Parent of New Hampshire
PO Box 622

Hanover, NH 03755
(603) 448-6393
FAX: (603) 448-6311

New Jersey

New Jersey Statewide Parent to
Parent
c/o SPAN, 35 Halsey Street,
4th Floor
Newark, NJ 07102
(973) 642-8100
FAX: (973) 642-8080

New Mexico

Parents Reaching Out
1000A Main Street
Los Lunas, NM 87031
(505) 865-3700
FAX: (505) 865-3737

New York

Parent to Parent of New York State
Balltown and Consaul Roads
Schenectady, NY 12304
(800) 305-8817
FAX: (518) 382-1959

North Carolina

Family Support Network of NC
CB#7340, Chase Hall
Chapel Hill, NC 27699-7340
(919) 966-2841
FAX: (919) 966-2916

North Dakota

Family to Family Project
UND School of Medicine and
Health
Science—PO Box 9037
Grand Forks, ND 58202
(701) 777-2359

Ohio

The Family Information Network
143 Northwest Avenue, Bldg. A
Tallmadge, OH 44278
(330) 633-2055
FAX: (330) 633-2685

Pennsylvania

Parent to Parent of Pennsylvania
Gateway Corporate Center
6340 Flank Drive, #1200
Harrisburg, PA 17112

(717) 540-4722
FAX: (717) 657-5983

South Carolina

Family Connection of South
Carolina
2712 Middleburg Drive, Suite 103-B
Columbia, SC 29204
(803) 252-0914
FAX: (803) 799-8017

Tennessee

Parents Encouraging Parents
5th Floor, C. Hull Building, 426
Fifth Avenue N.
Nashville, TN 37247-4850
(615) 741-0353
FAX: (615) 741-1063

Utah

HOPE-A Parent Network
2290 East 4500 South, Suite 100
Salt Lake City, UT 84117
(801) 272-1051
FAX: (801) 272-8907

Vermont

Parent to Parent of Vermont
1 Main Street, 69 Champlain Mill
Winooski, VT 05404
(802) 655-5290
FAX: (802) 655-3507

Virginia

Parent to Parent of VA
c/o Arc of VA
6 North 6th Street, Suite 403
Richmond, VA 23219
(804) 222-1945
FAX: (804) 222-3402

West Virginia

Common Bonds of West Virginia
1101 Hospital Drive
Hurricane, WV 25526
(304) 757-8465
FAX: (304) 757-1003

Washington

Parent to Parent Support Program
10550 Lake City Way NE, Suite A
Seattle, WA 98125
(206) 364-3814
FAX: (206) 364-8140