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Authors	Santelli, Betsy;Turnbull, Ann P.;Marquis, Janet;Lerner, Esther P.
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Parent to Parent programs: A unique form of mutual support

Parents of young children with special needs are thrust into the world of disability—a life experience with many strong emotional responses and challenges. Parent to Parent programs provide emotional and informational support to parents of children with special needs by matching a trained veteran parent in a one-to-one relationship with a parent newly referred to the program. This article reports the results of a national survey of veteran and referred parents participating in Parent to Parent programs and discusses how Parent to Parent support is an important part of comprehensive family-centered services for parents and providers. Key words: *mentor parents, mutual support, parent support, Parent to Parent*

Betsy Santelli, MEd

*Coordinator, Parent to Parent Projects
Beach Center on Families and Disability*

Ann P. Turnbull, EdD

*Professor of Special Education
Co-director
Beach Center on Families and Disability*

Janet G. Marquis, PhD

*Director of Research Design and Analysis Unit
Schiefelbusch Institute for Life Span Studies*

Esther P. Lerner, MS

*Data Management Coordinator
Schiefelbusch Institute for Life Span Studies
University of Kansas
Lawrence, Kansas*

WITH EMERGING EMPHASIS on family-centered services, service providers are learning from families about the kinds of supports that are the most helpful to them.^{1,2} When parents of young children with special needs and early intervention practitioners were asked about their preferences in early intervention services, parents most frequently mentioned the importance of professional sensitivity to families. Emotional and informational support, informality, flexibility, responsiveness, and acceptance were all given as examples of this sensitivity, as well as simply allowing parents of infants and toddlers the time needed to learn about and live within their new world of disability. Families also mentioned how important it was to find and have support from other families with similar children.^{2,3}

A unique model for personalizing family support services according to the needs and preferences of families exists in Parent to Parent programs.^{4,5} Parent to Parent programs provide factual information and emotional support to parents who have a child with special needs by establishing a one-to-one match between a trained veteran parent—someone who has had experience as a parent of a child with a disability—and a parent who is newly referred to the program. The referred parent generally has a child with a similar disability and has expressed an interest in receiving support from

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another parent who has "been there." The opportunity to share family experiences with others who understand because they have had similar experiences is an important source of support, and it is this opportunity that is the foundation of the Parent to Parent match.

Often at the time of the match, the referred parent has just been given the diagnosis or is just beginning a new era in the life of the child with a disability, such as the transition from the neonatal intensive care unit at the hospital to home or entry into an early intervention program or public school. The veteran parent provides emotional support to and shares information with the referred parent in a casual and flexible relationship. Many matches evolve into life-long connections, with the veteran parent becoming a reliable ally and friend.⁶ A mother explains:

Our daughter has been in hospitals constantly. Our support parents came down to see her in the hospital, call us a lot, send letters. The dad. . . even gave blood for our daughter's surgery. They took us out when our daughter was in intensive care and we were far from home. . . . They came to our daughter's first birthday party and have become some of our dearest, closest friends.

In an effort to learn more about Parent to Parent programs and the services they provide through the one-to-one match, the Beach Center on Families and Disability at The University of Kansas conducted a national survey of Parent to Parent program coordinators and the veteran and referred parents who are participating in these programs. The data from the programs participating in the survey describe 267 Parent to Parent programs serving approximately 20,000 families in 47 of the 50 states nationally. The vast majority of these programs are cross-disability, matching parents whose children have a wide range of physical, mental, and emotional disabilities, including chronic illness and acquired disabilities.⁴

A random sample of referred and veteran parents participating in the Parent to Parent programs who returned program surveys completed parent surveys and provided a wealth of information about the nature of their participation and their prefer-

ences for emotional and informational support. This article presents and discusses the data from referred and veteran parents who participated in the national survey to answer the following research questions:

- Who participates in Parent to Parent programs, and what disabilities are represented?
- How are one-to-one matches made, and what are the characteristics of the matched interactions?
- What types of emotional and informational supports are provided to and preferred by referred parents who participate in Parent to Parent programs?
- What supports are veteran parents receiving before and during their matches with referred parents?

This article also discusses how Parent to Parent programs can be a resource to both parents and providers as an important piece of a comprehensive, family-centered service system.

METHOD

Two questionnaires were used in the current study: one for parents who were participating in a Parent to Parent program as referred parents and one for parents who were serving as veteran parents. The survey for referred parents consisted of 46 questions, and the survey for veteran parents included 75 questions. Both surveys had a combination of closed and open-ended items as well as opportunities for parents to rank the importance of various items within some of the questions. Questions on both surveys were divided into five major categories: (1) participating family demographics, (2) reasons for participation in the program, (3) the nature of the match, (4) the types of emotional and informational support received and preferred through the one-to-one match, and (5) other program supports above and beyond the matched experience. The survey for veteran parents contained additional questions related to the veteran parent training. Both surveys were developed with the assistance of seven national leaders in Parent to

Parent who served on the advisory committee for the project and in accordance with respected mail survey development guidelines.⁷

A total of 704 referred parent questionnaires and 629 veteran parent questionnaires were sent out to parents by Parent to Parent program coordinators. Program administrators received instructions for randomly selecting 30% of their referred and veteran parents to receive the questionnaire and needed only to provide the address labels for the envelopes and then forward the packets on to the parents. Over the course of 15 months and in response to 2 reminder postcards that were sent to parents who had received but not returned surveys, completed survey booklets were received from 240 referred and 330 veteran parents, representing 115 different Parent to Parent programs from 43 of the 50 states. Each of these parents received a free audiotape from the 5th National Parent to Parent Conference, a certificate of recognition, and a summary of the survey findings for their important contributions to the project.

RESULTS

Family demographics

Of the referred parents and the veteran parents who were participating in Parent to Parent and who returned surveys, the greatest percentage (88%) of parents were Caucasian, with 12% representing a minority group. Moreover, most of the parents were part of a two-parent household (90%), and 35% had an annual income of over \$50,000. Data from the national census indicate that of all families in the United States, 75% are Caucasian, 78% are two-parent households, and 24% have annual incomes of over \$50,000.⁸

Parent to Parent programs are providing emotional and informational support to parents whose sons and daughters have a wide range of disabilities, as is depicted in Table 1. Nearly two thirds (64%) of the disabilities represented are moderate or severe.

Nature of the match

Referred parents found out about Parent to Parent programs from many different referral

Table 1. Disability representation

Type of disability	Parents reporting (%)
Developmental delay	31
Down syndrome	29
Mental retardation	23
Learning disability	20
Visual impairment	16
Cerebral palsy	16
Multiple disabilities	15
Chronic illness	15
Prematurity	10
Hearing impairment	10
Epilepsy	8
Technology supported	5
Autism	3

sources, and these connections are outlined in Fig 1. The vast majority of parents who marked *Other* indicated on their surveys that they referred themselves after having seen a brochure, poster, or some other printed information about the program. The greatest percentage (29%) of parents were referred to the program by a member of the medical profession (nurse and/or physician).

Once a referred parent is connected to a Parent to Parent program, the program coordinator considers several different factors to ensure a successful match. Table 2 provides information about the factors that referred parents reported to be the basis of their match, as well as the percentage of referred parents who ranked each factor as being *preferred* (one of the top three most important variables in their match). Similar disability and family issues are used most often *and* ranked as preferred by the greatest percentage of referred parents.

Once a referred parent and a veteran parent are matched, the matched relationship evolves in an individualized manner based on the needs and preferences of the referred parents. The timing and frequency of contacts, as well as whether the contacts are in person or by telephone or mail, are different for each match. Some Parent to Parent matches are short term, lasting only a few days and having only a few contacts, while others last for much longer and have many contacts. Of the

referred parents responding to the survey, 50% are in matches that have lasted more than 1 year, and 56% have had at least 7 contacts.

Supports for referred parents

Table 3 presents the emotional, informational, and other program supports that were provided to and preferred by referred parents. A preferred support is one that parents ranked as one of the three most important to them.

Given that Parent to Parent programs have as their foundation the provision of support from someone with similar experiences who is available to listen, it is not surprising that this type of emotional support was listed most often as being provided in the match (72%) and ranked most often by referred parents as being preferred (66%).

Table 3 also describes the types of informational support that referred parents reported as being provided to them and how they ranked these supports in importance. Information about the disability and information about living with and caring for a family member with special needs were mentioned equally by referred parents (60%) as being provided to them, with 63% of the referred parents ranking disability information as preferred and 58% ranking information about living and caring for their son or daughter with a disability as a preferred support.

Many Parent to Parent programs provide a comprehensive array of support services in addition to the one-to-one match.⁴ Table 3 presents information on the supports above and beyond the one-to-one matched experience that were provided to and preferred by referred parents. Group meetings, both

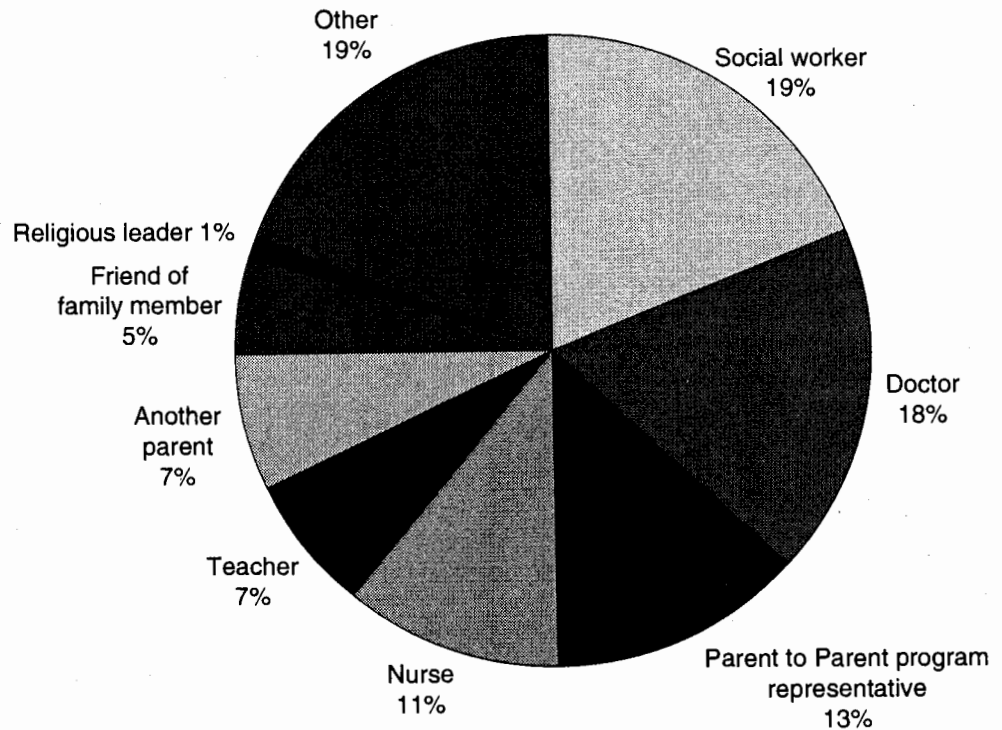


Fig 1. Connections with Parent to Parent.

Table 2. Factors in parent matches

Factors	Used for parents (%)	Preferred by parents (%)
Family members have similar disabilities	76	76
Families faced similar problems	55	63
Family members with disability are same age	36	38
Family structure is similar	29	9
Parents are same age	28	13
Families live close by	27	18
Veteran parent could respond in 24 hours	25	24
Cultural/ethnic backgrounds are similar	23	9
Education and income level are similar	18	8
Families are similar size	17	4
Families both speak English as a second language	1	0

for educational and emotional support, were reported by the greatest percentage of parents (69% and 65% respectively) as being offered by their program and were preferred by the largest percentages of referred parents (48% and 47% respectively). While only 27% of the parents related that their program provided a 24-hour telephone "warm line,"

this service was ranked as preferred by the third highest percentage (27%) of the referred parents.

Training for veteran parents

Veteran parents are the backbone of Parent to Parent programs, volunteering their time to provide emotional and informational support to parents

Table 3. Supports provided by Parent to Parent programs

Supports	Provided by program (%)	Preferred by parents (%)
Emotional		
Someone to listen and understand	72	66
Helping in feeling less alone	63	35
Knowledge of others who are doing OK	58	34
Hope for the future	59	33
Way to deal with stress	43	21
Problem-solving support	45	20
Informational		
Disability information	60	63
Care for child	60	58
Ways to find and get services	45	54
Community resources	50	47
Financial information	27	20
Respite care information	28	17
Other program supports		
Group meetings for emotional support	65	48
Group meetings for education	69	47
24-hour warm line	27	27
Social events	63	23
Activities for other family members	31	11
Chance to tell others about program	36	9

newly referred to the program, and most Parent to Parent programs (76%) train veteran parents for their important role.⁴ Fig 2 presents information on the number of hours of initial training that veteran parents receive from their programs, with 44% of veteran parents indicating that they receive 10 or more hours of training.

Veteran parent training covers a wide range of topics as is depicted in Table 4, with over 90% of the veteran parents reporting that they were provided with training in listening skills (94%); training in communication skills (93%); and an orientation to the Parent to Parent program goals, activities, and philosophy (92%). By far the greatest percentage of veteran parents (53%) ranked the training in listening skills as being preferred (one of the top three most important content areas).

Once matched and as their matches evolved, veteran parents indicated that they were provided with ongoing support and informal training from a variety of people connected to the program—the program coordinator (82%) and another veteran parent (57%) being mentioned most often.

DISCUSSION

Participants in Parent to Parent programs

Parents who are participating in a Parent to Parent program as either a referred or a veteran parent tend to be Caucasian mothers from two-parent families with an income above \$35,000. That more minority parents are not involved in Parent to Parent is a challenge not only for Parent to Parent but for other parent support efforts as well.⁹ Further

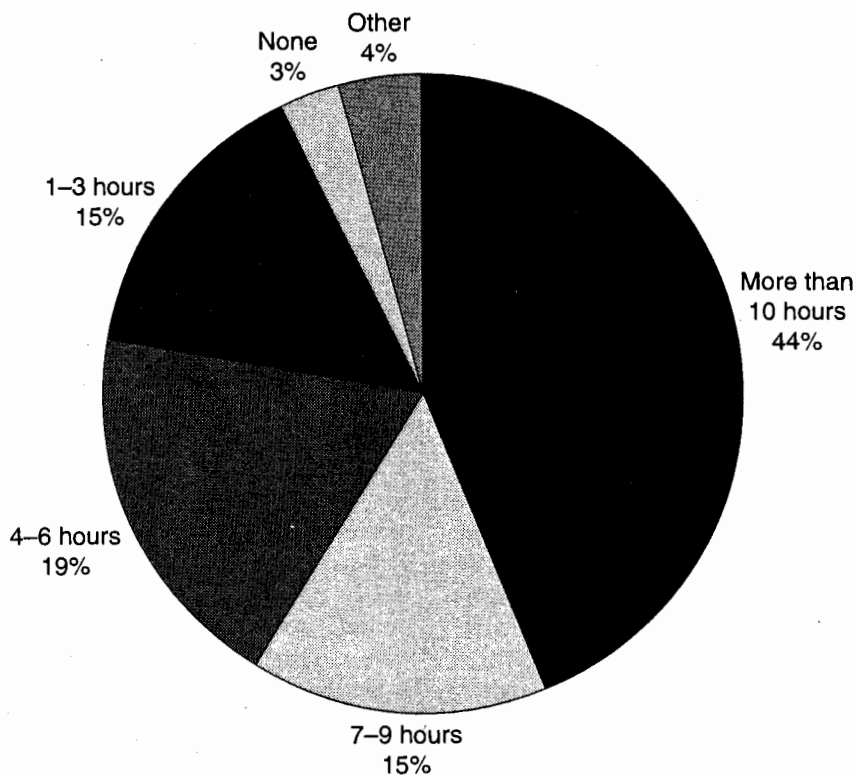


Fig 2. Hours of veteran parent training received.

Table 4. Content of veteran parent training

Content area	Provided by program (%)	Preferred by parents (%)
Listening skills	94	75
Communication skills	93	55
Orientation to program	92	11
Adjustment to the diagnosis	86	34
Community resources	83	32
Information about disabilities	81	16
Positive philosophy	80	27
Disability organizations	80	8
Referral process	74	13
Self-awareness	60	8
Financial information	58	4
Advocacy training	56	13
Leadership training	39	1
Cultural diversity training	37	2

research is needed to understand more fully why minority parents are underrepresented in Parent to Parent and other parent support programs. Perhaps because the first Parent to Parent programs were coordinated in the early 1970s by middle-class Caucasian mothers, replication efforts were most easily undertaken by mothers with similar characteristics.¹⁰ Many Parent to Parent programs recognize the challenges of reaching families who are not fully represented in the service system, and several of these programs have developed some innovative outreach strategies for involving families of diverse racial, cultural, and ethnic backgrounds. Some successful strategies include involving a respected member of the community as the program coordinator, preparing printed materials in languages other than English, subsidizing long-distance telephone calls between veteran and referred parents, and adding the Parent to Parent component to an existing successful family resource center.¹¹

Nature of the match

Referrals to a Parent to Parent program are vital to the success of the program, and parents learn about the Parent to Parent opportunity through a wide

variety of sources. Perhaps because physicians often deliver the diagnosis of a disability to the family, and social workers connected with many different service provider agencies often provide ongoing support to the family, these professionals are mentioned most often by parents as referral sources. While Parent to Parent programs consider their public relations efforts to be among their most important activities, because 55% of Parent to Parent programs have annual budgets of less than \$5,000, widespread distribution of program brochures and literature is often not possible.⁴ Service providers thus may need to be proactive about finding a Parent to Parent program for referrals. Local interagency coordinating councils (LICCs) coordinating services for infants and toddlers with special needs are often aware of the existence of a Parent to Parent program in their communities. The Beach Center maintains and updates a directory of Parent to Parent programs that provides contact information for several hundred Parent to Parent programs nationally.

Matches in Parent to Parent programs are made with careful consideration of many different commonalities that a referred parent and a veteran parent may have. Referred parents report being matched most often (and preferring matches)

around similar disability and family issues, with age of the family member with special needs being listed as used and preferred the next most frequently. Since the capacity for Parent to Parent programs to match around similar disability and family issues is directly related to the number and diversity of trained veteran parents within the program, Parent to Parent programs actively recruit parents with diverse family and disability experiences to serve in the veteran parent role. Service providers are in a good position to discuss the veteran parent opportunity with parents whose children they treat, and with the permission of the parents, to refer any interested prospective veteran parents to a Parent to Parent program.

Referred parents also mentioned that they preferred having the veteran parent able to contact them within 24 hours of their match. Once the decision is made by a referred parent to participate in a match, it may be that there is some anxiety about what the matched relationship will bring. Parent to Parent programs respond by encouraging veteran parents to contact the newly referred parents just as soon as possible after the initial referral. Once the Parent to Parent match is made, support can be (and is) activated at any time and through any type of contact (eg, in person, by telephone, by mail), thus providing an easily accessible and responsive support system for parents. A referred parent describes the nature of her match: "I think Parent to Parent is an invaluable support system, especially for parents who have just found out that their child has or might have a disability. It is so important to not feel alone, and to have someone to turn to who can listen and not judge. My veteran parent initiated our first phone calls just to say hello and ask how things were going until I got comfortable calling her. She and I, our husbands and our sons with disabilities are now good friends and always will be."

Supports for referred parents

Just as the nature and development of each one-to-one match is unique, so too the supports that referred parents are provided and prefer are as

individualized as the parents themselves. While most parents mention the emotional support of having someone who shares their experiences to listen and understand, information about disability and day-to-day living issues, and group meetings for emotional and educational support as being important parts of their match, each match fulfills individualized needs. Parent to Parent programs provide a broad range of supports, because they recognize that even those supports that are ranked as preferred by only a small percentage of parents are very important to those individual parents. However, the parental preferences for the various supports and services that are reported in Table 3 may be helpful to new Parent to Parent programs as they prioritize the development of new components.

Training for veteran parents

Veteran parent training is recognized by Parent to Parent programs as being important not only for ensuring the quality of support that is provided to referred parents, but also for increasing the credibility of the program with potential referral sources. With families in early intervention indicating their preferences for relationships that are informal, individualized, built on trust, and responsive to family needs, veteran parents who are trained specifically in communication and listening skills and who have years of personal and practical experiences with disability issues can serve as important links with early intervention professionals and with parents whose young children are receiving services. Veteran parents have the skills, the wisdom that comes only with personal experiences, and the ongoing support from the Parent to Parent program to be important and credible resources to other parents as well as to providers in early intervention services across the country.

CURRENT AND FUTURE DIRECTIONS

The national survey provided important descriptive information about Parent to Parent programs—information about where programs are, the types of services they provide, and anecdotal information

from participating parents about how the Parent to Parent experience has been helpful to them. This information was used to design a study to determine the efficacy of Parent to Parent support for referred parents—a study that is being carried out by a participatory action research team of parents and researchers in four different states.^{12,13}

Additional Parent to Parent research that the Beach Center is conducting includes a 5-year study to determine the longitudinal efficacy of Parent to Parent support for referred parents, veteran parents, and the child with a disability, and a national survey of statewide Parent to Parent programs to learn more about how they have developed and how they provide technical assistance to local programs.



Health care and early intervention professionals are in a unique position to benefit from Parent to Parent support and to contribute to its increased availability to families. Service providers benefit from Parent to Parent programs because these programs offer important connections between and among parents, and through these connections, they provide emotional and informational support from one parent to another in ways that are preferred by families. With the rapid development of early intervention services and the increased emphasis on family-centered services, professionals may sometimes feel caught between believing in the importance of involving and responding to families and the realities of staff time and experiences. Parent to Parent programs provide experienced veteran parents who volunteer their time to share with other parents in ways that only parents can. One professional who is working closely with a Parent to Parent program speaks about the benefit of Parent to Parent for his staff:

When the Parent to Parent program was established, we knew that the program would be of assistance for families, but we didn't realize until later that it would also be of great assistance to the staff. As professionals, we often feel

inadequate because we cannot truly understand what families are going through since we haven't actually experienced what they have. Our staff became aware that this program could fulfill a need for families that they as professionals could not. In this way the program supports the role of the professional as well as supporting the family.

Providers can contribute to Parent to Parent by referring parents to a Parent to Parent program and sponsoring a Parent to Parent program. Parent to Parent programs rely on referrals from service providers. When medical and other early intervention personnel are aware of a Parent to Parent program and tell parents about the opportunity to be matched with another parent, referred parents can begin receiving this important support at the time of birth or early diagnosis of their child.

Approximately half of the Parent to Parent programs responding to the national survey are sponsored by a service provider agency, and there are many ways in which agencies can sponsor a Parent to Parent program at no additional cost to the agency.⁹ A sponsoring agency may contribute to a Parent to Parent program by

- allowing the Parent to Parent program to use its not-for-profit status for fundraising and grantwriting purposes;
- providing meeting room space or a telephone line;
- assisting with training for veteran parents; and
- promoting the program to other professionals and parents.

All of these may give the program more credibility with potential referral and funding sources.

As service providers and parents collaborate to provide a system of family-centered early intervention services in their communities, perhaps the one-to-one matched opportunity provided by Parent to Parent programs can become an established component of the service system. Parent to Parent programs and early intervention efforts in partnership can provide families with a comprehensive array of professional and parent supports and services broader than either parents or professionals can provide alone.

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