

Section I

Developing and Expanding a Statewide Parent to Parent Program

2000

ACKNOWLEDGEMENTS

This manual is the result of a wonderful multi-year collaboration between the directors of statewide Parent to Parent programs and the Beach Center on Disability at The University of Kansas.

Statewide Parent to Parent program directors (and local program coordinators in their states) responded to surveys developed by researchers at the Beach Center. Their survey responses generated a wealth of descriptive data about their programs - their administrative and organizational structures; funding sources and budgets; methods of finding and training veteran parents, strategies for implementing the one-to-one match between veteran parents and parents seeking support from another parent who has been there; other program activities; designs for delivering technical assistance to local programs; and collaborative partnerships.

For the last several years in preparation for the International Parent to Parent Conference, statewide Parent to Parent program directors have also submitted descriptive information the Beach Center to support the development of the *Statewide Parent to Parent Program Digest*. Statewide Parent to Parent program directors have also been meeting annually with each other and Beach Center staff to share best practices and resources.

Without the support and generous sharing of statewide Parent to Parent program directors, this manual would not have been possible. Special thanks go out to each of you.

Without the commitment of the Beach Center and its co-directors, Ann and Rud Turnbull, to research that makes a difference to families who have a child or young adult with a disability, chronic illness, or other special health care needs, the resources and research expertise that have contributed to the success of the Parent to Parent research would not have been available. Special thanks go out to each of you.

Betsy Santelli, Director
Parent to Parent Projects
Beach Center on Disability

ADDENDUM

We are sad to share that Betsy Santelli, who provided such responsive and caring support to the Parent to Parent network, died on October 31, 2002. Her legacy lives in the hearts of everyone who knew her and respected her giving way of being on this earth. We hope you will continue to benefit through this manual from her Parent to Parent contributions. Jane Gnojek at the Beach Center is the current contact for Parent to Parent updates. Please communicate with Jane about updates to this manual related to program contact information and the list of Parent to Parent Gifts and Talents in Appendix. Jane's email is jgnojek@ku.edu, and her phone number is 785-864-7600.

Ann and Rud Turnbull
Co-Directors, Beach Center

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Parent to Parent Programs as a National Resource

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 1-1 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.

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 1-1 connections between parents. The program grew rapidly and within a few years the founders received a federal grant to train others to replicate the Pilot Parent model. Parent to Parent programs began to spring up nationwide, fueled by the energies and commitments of parents who believed fervently in their importance.

In the fall of 1988, the Beach Center on Disability at The University of Kansas initiated a national survey of Parent to Parent programs to discover more about the evolution of the Pilot Parent model. Results from the survey indicate that the number of Parent to Parent programs has grown from 1 – the Pilot Parents Program at the Greater Omaha Arc in Omaha, NE in the early 1970’s – to 500 or more active programs that today are offering services to families through the 1-1 Parent to Parent match. Over 50,000 parents are participating in Parent to Parent programs across the nation.

These active Parent to Parent programs exist in every region of the country and we received at least 1 survey back from 48 of the 50 states. Parent to Parent programs range from very small ones serving just a few parents, to very large ones serving several hundred families. The average size Parent to Parent program is providing support to between 13 and 26 referred parents. 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 over \$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. All Parent to Parent programs provide emotional and informational support to families through the 1-1 Parent to Parent match between a veteran parent and a newly referred parent.

The vast majority of these programs are cross-disability. Of the families participating in Parent to Parent as referred parents, 85% have a child with special needs who is younger than 12, although an increasing number of veteran programs are now matching families with adolescents and young adults. 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, as well.

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. Parents and researchers worked together to design the study, write the grant application; and carry out this important study involving 400 parents nationally. Dr. George Singer, University of California at Santa Barbara, was the director of this national study. 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 over 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. Interviews with parents suggest that the kind of support Parent to Parent offers is unique and cannot come from any other source. Based upon statistically significant quantitative data, the research team recommends that Parent to Parent support be included as one essential component of a comprehensive family support system.

Local Parent to Parent programs exist in every state in the United States, and in 30 states there is also a statewide Parent to Parent program. Statewide Parent to Parent programs provide information and emotional support through Parent to Parent matching across the state. They also often provide training and technical assistance to the 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 federally-funded Parent Training and Information Center (PTI). PTI's 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. (Each state has at least one PTI.) As the PTI, the statewide Parent to Parent program provides information and training to parents around the educational needs and rights of children with disabilities and supports parents to act as full partners in educational decision making on behalf of their child. In other states, the statewide Parent to Parent program has 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; and 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; whereas in other states, the statewide Parent to Parent program is de-centralized and provides resources and technical assistance to a network of autonomous local programs. No two statewide Parent to Parent programs are exactly alike, and there is no one right way to develop a program. The statewide Parent to Parent program in your state will be uniquely your own.

The Beach Center has conducted a survey of statewide Parent to Parent programs to learn more about the services they provide to parents and local programs, how they are funded and

staffed, their organizational structure, and program developed materials they have to share. The results of this survey, and the wisdom and experiences of statewide Parent to Parent program directors, form the basis for this manual and suggest some issues and strategies to consider as one develops/expands a statewide Parent to Parent program.

If, as you use this manual, you want to suggest changes or additions that need to be made, please contact:

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GUIDELINES FOR STARTING A STATEWIDE PARENT TO PARENT PROGRAM

Starting a statewide Parent to Parent program begins with a commitment to the value of parents supporting other parents, and to the idea of the 1-1 match between a veteran parent and a referred parent. Strengthened by these commitments, a core group of parents, or a group of parents working collaboratively with supportive professionals, can successfully start a new statewide Parent to Parent program by taking the following considerations into account:

- Learning the specifics about Parent to Parent and its presence in your state
- Consider organizational models of statewide Parent to Parent and determine what fits best in your state
- Determining leadership
- Deciding about sponsorship/agency support
- Determining roles and responsibilities
- Considering funding options
- Recruiting and training veteran parents
- Establishing the referral system and informing service providers/referral sources
- Implementing the match and providing follow-up support for the match
- Adding other program components beyond the match
- Providing technical assistance to local programs
- Building collaborative partnerships statewide
- Learning about statewide Parent to Parent resources

Learning the Specifics About Parent to Parent and its Presence in Your State

As you begin to plan for a statewide Parent to Parent program, remember that there are resources to help you get started and that you don't have to do it all by yourself from scratch. There are many excellent information and training materials on Parent to Parent program development and implementation available from established statewide Parent to Parent programs. See Appendix A of this manual, Statewide Parent to Parent Program Listings and Resources, and/or contact the Beach Center on Disability at The University of Kansas at (785) 864-7600 for further information.

You may also want to find out whether or not there are any currently existing Parent to Parent programs that are providing the one-to-one match between a veteran parent and a referred parent in your state. The Beach Center maintains and updates annually a list of local Parent to Parent programs in each state, and one way for you to locate local Parent to Parent programs in your state is to contact the Beach Center at (785) 864-7600. You may also find it helpful to talk with other parents and providers about parent support programs they may know of in your own region or perhaps in other regions of your state. The Parent Training and Information Centers (PTI) in your State may maintain lists of resources for parents statewide and they may know of Parent to Parent programs in the state. Similarly representatives of state agencies (either those with a specific disability focus such as Down syndrome, or non-categorical programs such as The Arc) may know of local programs offering Parent to Parent support. If you are able to attend statewide conferences for parents and professionals involved in the families and disability field, you may learn about Parent to Parent programs in other parts of your state.

If there are already some local Parent to Parent programs in your state, you may find it helpful to bring them into the early planning at the very beginning. These local program coordinators will be wonderful resources to an emerging statewide program, and their early participation in the planning should minimize any later turf issues. Even if the local program coordinators do not want to take an active role in the development of the statewide program, but rather just want to keep serving families locally, they will appreciate being asked and being informed about developments at the state level.

Consider Organizational Models of Statewide Parent to Parent

While each of the 30 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 and/or local programs.

Some statewide programs are **centralized** with all of the major program activities happening at the state level. In a centralized program, there are no local Parent to Parent programs in communities across the state, but rather there are trained supporting parents residing in communities. The statewide program provides these local supporting parents with the training they need to serve as supporting parents, and then matches supporting parents with parents who

are referred to the program. Some communities may have only one supporting parent, others may have more, but there is no local autonomous Parent to Parent program in the community.

Other statewide programs are more **de-centralized**, 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.

Many programs fall **somewhere in between** on the continuum. Some programs are more centralized and others have adopted an organizational structure that is more de-centralized. Some programs are more centralized in some activities and more decentralized in others. Over time, perhaps in an effort to enhance its services statewide or to respond to funding realities, a statewide program may adapt its organizational structure becoming either more or less centralized or de-centralized.

Centralized Statewide Parent to Parent Programs

On one end of the continuum, there are statewide programs such as Parent to Parent of Vermont that are completely centralized. Parent to Parent of Vermont began in 1984 as a peer support program of the Champlain Arc providing one-to-one parent support to parents in Chittenden County. In 1988, in response to the need for parent matching across the state, Parent to Parent of Vermont incorporated as a public nonprofit statewide support and information network for families whose children have a chronic illness or disability or who have been born prematurely.

Because Vermont is a small state with all of its many small rural communities accessible by car within a few hours of Chittenden County, coordinating 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 maintain the roster of trained supporting parents and make all the matches. Once 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 of the training and promotional materials that are needed and used throughout the state. Brochures, public service announcements (PSAs), 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. Given the geography and demographics of the state of Vermont, it makes perfect sense for the statewide Parent to Parent program to be centralized.

De-centralized Statewide Parent to Parent Program

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.

In 1985, with a grant from the North Carolina Council on Developmental Disabilities, a physician and a social worker, developed two local Parent to Parent programs and an initiative to involve families in the education of medical students. From this beginning, FSN-NC has evolved to include a statewide network of 25 local Parent to Parent programs for which FSN-NC's central office serves as the coordinating arm.

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 NC either have their own 501c-3 non-profit 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 may also provide the training to the supporting parents. Some of the local programs do just parent matching while 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 match cannot be found by a local coordinator, FSN-NC can search its own statewide database of parents to make a statewide match.

Given the size of North Carolina, the distance between communities, the diversity of its communities (some very large and urban, others small and rural), and the interest of parents in several communities to develop their own local Parent to Parent program, it makes perfect sense for North Carolina to adopt a de-centralized model for its statewide Parent to Parent program.

Somewhere In Between

Most statewide Parent to Parent programs fall somewhere in between a completely centralized program and a completely de-centralized program. These programs offer statewide support and services to parents and/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 over 75% of statewide Parent to Parent programs have at least two regional coordinators.

Parent to Parent of Georgia is an example of a program that started as a decentralized program, moved toward a more centralized structure, and is now somewhere in between.

Parent to Parent of Georgia started in 1980 as a three-year project of the Governor's Council on Developmental Disabilities. A cadre of parents trained and supported parents in communities across Georgia to develop their own local Parent to Parent programs. For several years, these local Parent to Parent programs handled their own referrals and matches, with technical assistance from the central office in Atlanta. Over time, however, some of these programs lost their coordinators and when replacement coordinators could not be found, the local programs ceased to exist. To ensure that parent matching services continued to exist for parents across the state, even in communities without a local program, Parent to Parent of Georgia began to move toward a more centralized model.

Parent to Parent of Georgia now has a toll-free number that connects all families to the statewide office, with all parent referrals coming directly to the statewide office. Four paid regional coordinators (two in Atlanta and two in satellite offices in Southeast and Southwest Georgia) make parent matches for parents living within their regions. The statewide office maintains a statewide database of parents and assists with matches when a local or regional match cannot be found. Regional coordinators also provide training to parents in their region who wish to be supporting parents and assist with promotional activities on behalf of Parent to Parent of Georgia. Currently Parent to Parent of Georgia has trained over 2,000 parents representing 140 of Georgia's 159 counties. Clearly the shift from a de-centralized to a more centralized model with regional activities has meant that Parent to Parent of Georgia has been able to continue to meet the needs of parents throughout the state of Georgia.

Most likely the organizational structure that seems most appropriate in your state will depend on the *lay of the land* in your state. You may want to consider the following:

- The size and geography of your state. In smaller states it is quite possible for all of the Parent to Parent activities to be provided statewide from the state office – shorter distances from one end of the state to the other make it feasible for statewide program staff to get around to local communities to train supporting parents. Statewide programs in larger states will need to consider the distance factor in delivering training and support to local communities. In smaller and/or more rural states the local communities may be quite small and may not have enough parents to support the development of a local program, whereas in larger more

populated states, many communities will have more than enough parents to support a local program.

- Whether or not there are existing Parent to Parent programs in your state and what the preferences of these programs are for statewide support. Sometimes an existing Parent to Parent program in a state that is developing a statewide program may wish to retain its full autonomy – in which case a centralized model most likely would not work.
- Other organizations providing support to families and how these services are organized across the state. It may make sense to organize the statewide Parent to Parent program to fit in with existing systems. For example, Parent to Parent of New Hampshire took advantage of existing (and funded) regional family support councils and was able to add the Parent to Parent component in each region.

As you consider where your emerging statewide program may fit on the continuum, 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 Appendix A. The *Statewide Parent to Parent Gifts and Talents* listing indicates which statewide Parent to Parent programs have expertise in which organizational models. 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 that have adopted models similar to those you are considering may give you some helpful ideas.

Determining Leadership

Once you have identified existing local Parent to Parent programs, then you may also want to consider who else in your state (1) might be interested in being a part of the development of the statewide program; (2) might use the services of a statewide Parent to Parent program by referring families; (3) might be able to help you secure funding for the program; (4) is a part of the existing statewide service system for families who have a family member with a disability.

Many statewide Parent to Parent programs are launched simply by bringing the key stakeholders together for an informational meeting and a chance to brainstorm together about the important role a statewide Parent to Parent program can play in the state. You will also want to be sure that parents are well represented at this meeting as well. At the meeting you may want to include the following items on your agenda:

- Overview of Parent to Parent support and how it is different from other types of parent support. Invite parents to share their personal experiences.
- Statewide Parent to Parent programs – how they look in other states and what they do for families and for local Parent to Parent efforts. This information is available from the Beach Center on Disability.

- Current resources for families in your state and how Parent to Parent might collaborate with and enhance these efforts.
- State funding options for Parent to Parent in your state – both public and private funds.
- Your vision for statewide Parent to Parent in your state.
- Planning next steps.

Parents in New Jersey started just this way, and at the end of their initial meeting with key stakeholders, the representative from the Department of Public Health promised significant funding support for the statewide program! Another important reason for beginning this way is that it is participatory, and when other key players in the realm of family support in your state have the opportunity to be involved (even if they choose not to), they will feel less threatened by the newly developing statewide Parent to Parent program and more invested in its success.

One key to the success of a statewide Parent to Parent program is parent leadership in the development and implementation of the program. A visible parent commitment to the program from the outset will enhance the program's credibility in the eyes of other parents. When professionals have the opportunity to learn from parents in leadership positions about the unique support provided by Parent to Parent programs, they are often able to support the development of the statewide program in ways that enhance the program's credibility in the eyes of other professionals. Most statewide Parent to Parent programs were started by a team of parents and professionals in partnership. When asked who started their statewide Parent to Parent programs, 89% of the respondents to the survey of statewide Parent to Parent programs directors indicated that parents started the programs and 72% mentioned that professionals also had a role in starting the program. As you pull together your leadership team, think about other parents who might work with you and consider which professionals might be your reliable allies as well.

Deciding About Sponsorship/Agency Support

A statewide Parent to Parent program may be established as an entirely volunteer organization with its own not-for-profit status, or it may be sponsored by a service provider agency, disability organization, or existing parent group. Data from the survey of statewide Parent to Parent programs indicate that 19% of the responding statewide Parent to Parent programs are sponsored by another agency, and 81% are autonomous. Whether to seek sponsorship is an important early decision, and the advantages and disadvantages of both a sponsored and a non-sponsored status need to be considered carefully.