

Section VI

Developing and Expanding a Statewide Parent to Parent Program

2000

Table of Contents for Section IV

Appendix F.....98
Appendix G.....112

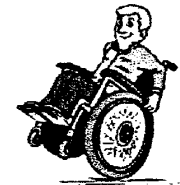
APPENDIX F

Sample Program Brochures



alliance of support for cooperative efforts in networking for people with disabilities

Parent to Parent of Florida

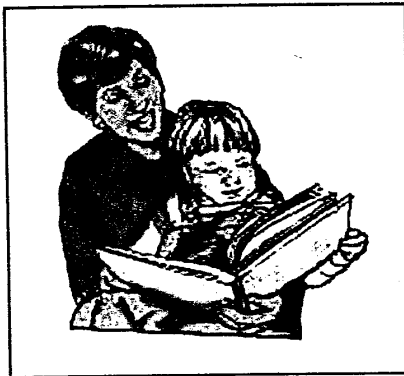


History

Since 1985, the Florida Parent to Parent Project has provided information, resources, referrals, training and technical assistance to support groups of parents of children with disabilities or special needs. In 1996, the name of the project was changed to ASCEND!, and expanded to include assistance to groups of adults with disabilities and/or their parents.

Parent to Parent Concept

Parents of children with special needs, who have come to accept and understand their child's disability, are one of the best sources of information and emotional support for other parents of children with special needs.



Information/Resources/Referrals

- Toll-free line available anywhere in Florida
- Extensive library of books, articles, files, CD's, and databases, as well as internet access to find the information you need

Technical Assistance

If you are interested in starting a Parent to Parent support group, we can help!

- Information, samples, and tips on best practices
- Support groups don't have to "reinvent the wheel"
- Groups can be included in our database, so we can refer local parents.
- These same benefits are available to groups of individuals with disabilities themselves, who would like to start a group for support, advocacy, and/or socialization.

Affiliation

Your new or existing support group can choose to sign an Affiliation Agreement with FND.

- Become part of a statewide network
- Benefit from the expertise of other groups that have the same goals.
- Receive newsletters, information about upcoming events or legislative alerts
- Become eligible to apply for a \$200 mini-grant
- Access free Support Parent Training manuals (as supplies last).

There is a growing community of parents online. FND has a website with hundreds of links to organizations and resources all over Florida and beyond.

- Main website: <http://www.fndfl.org>
- Subscribe to our email list & get "in the loop"
- Resources by region
- Online Chat (every 3rd Wednesday of the month, 10am & 9pm)

Support Parent Training

People join support groups for one of two reasons: Either they feel they need support, or they feel they are in a place to give support. Matching parents up one-on-one has been proven very successful in providing parents who are in crisis with a very special relationship which gives them information, validation, encouragement and often the empathy and understanding that no one else can.

If your support group has, or would like to start a parent matching program, we strongly recommend that you hold Support Parent Trainings for your veteran parents. We have a network of Support Parent Trainers in Florida who are available to facilitate this training for your group.

This training covers topics such as:

- Active Listening Skills
- Confidentiality
- The States of Grief
- Coping with Emotions
- "Do's and Don'ts" lists
- Sample forms for tracking calls
- Detailed description of the referral process
- Recommended procedures
- List of state disability organizations & resources

Friend to Friend

- Join FND's statewide parent matching network!

What is Parent to Parent?

Parent to Parent happens whenever and wherever one parent of a child with a disability or special health care needs offers or receives support from another parent. When you call Family TIES you will speak with another parent.

If you would like to be matched with a parent of a child with the same diagnosis or health concern, or if you have had more experience with your child's disability and feel you can offer support to another parent, please fill out the form below.

- I would like to be matched with another parent who has experience with _____
- I would like to hear about being a Family TIES support parent.

A Family TIES coordinator will be calling you for more information.

Please return to:

Polly Sherman
Family TIES Network Director
Massachusetts Department of Public Health
109 Rhode Island Road
Lakeville, Massachusetts 02347

Parents Are Our Strength

Family TIES welcomes your ideas. Please feel free to contact any of the Parent Coordinators listed below.

Family TIES Coordinator

Massachusetts Department of Public Health
Western Regional Office
23 Service Center
Northampton, MA 01060
413-586-7525; 1-800-445-1255

Family TIES Coordinator

Massachusetts Department of Public Health
Central Regional Office
180 Beaman Street
West Boylston, MA 01583
508-792-7880

Family TIES Coordinator

Massachusetts Department of Public Health
Boston Regional Office
Lemuel Shattuck Hospital
180 Morton Street
Jamaica Plain, MA 02130
617-727-1115; 617-727-1116

Family TIES Coordinator

Massachusetts Department of Public Health
Southeast Regional Office
109 Rhode Island Road
Lakeville, MA 02347
617-727-1440; 508-947-1231

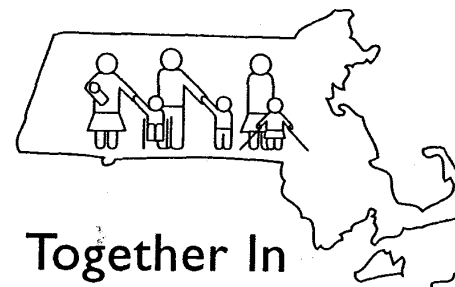
Family TIES Coordinator

Massachusetts Department of Public Health
Northeast Regional Office
Tewksbury Hospital
Tewksbury, MA 01876
978-851-7261; 617-727-7908

Family TIES Coordinator

Massachusetts Department of Public Health
Metrowest Regional Office
5 Randolph Street
Canton, MA 02021
781-828-7190; 781-828-7700

Family TIES of Massachusetts



Together In Enhancing Support

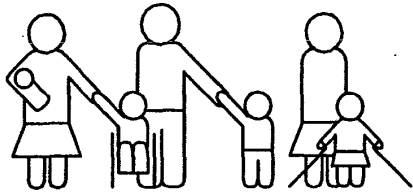
*Information and support network for
families of children with special needs*

Southeast

Joanne Spencer
Family TIES Coordinator
Massachusetts Department of Public Health
Southeast Regional Office
109 Rhode Island Road
Lakeville, MA 02347
tel: 617-727-1440 or 508-947-1231
fax: 617-727-9296
e-mail: joanne.spencer@state.ma.us

**Call 1-800-905-TIES
or visit our web site
www.massfamilyties.org**

About Family TIES



Family TIES is a statewide information and support network for families of children with disabilities or chronic illness. It is supported by the Department of Public Health, Bureau of Family and Community Health, Division for Children with Special Health Care Needs, in collaboration with the Federation for Children with Special Needs. Family TIES is also a member of the Massachusetts Network of Information Providers which is a statewide network of agencies that provides information, referral, and services for individuals with disabilities.

How We Can Help

We want you to know that you are not alone. As parents of children with special needs, we realize that the most powerful source of support is other parents.

Sharing up-to-date information can provide all family members with knowledge and skills that can help to improve our children's opportunities.

Family TIES Is Here for You

Regional Parent Coordinators are available to help anyone who is involved in caring for a child with disabilities or chronic illness. Please feel free to call or write the Coordinator for your area. The toll free number for Family TIES in Massachusetts is **1-800-905-TIES**; additional numbers and addresses are on the other side of this brochure.

Family TIES Parent Coordinators will:

- Provide up-to-date information and resources
- Match you with another parent
- Inform you of lectures, workshops, and conferences by adding your name to our mailing list
- Locate a parent support group in your area
- Invite you to our Annual Statewide Parent Networking Conference.

Family TIES does not offer medical advice, nor does it make referrals to any particular physician, clinic, or agency. We provide options by informing families of their community resources.

Family TIES Mailing List

If you would like to be on the mailing list for Family TIES activities, please fill out this form and return it to the address listed on the back.

Your Name _____

Address _____

TEL: _____

FAX: _____

e-mail: _____

Parent/Family member

Professional

Child's name: _____

Date of birth: _____

Disability: _____

I am interested in learning about:

Support Groups _____

Workshops on _____

The Federation for Children with Special Needs

Information on _____

I would like to talk to a Family TIES coordinator:

yes no



Who Contacts Parent to Parent?

Parents, pediatricians, nurses, teachers, social workers, friends - anybody.

Some Comments on Parent to Parent

"I have really learned a lot about myself and what I can deal with and what I can't by working with Parent to Parent."

"The value of talking to a parent who's 'been there' is immeasurable, critical to raising a child with special challenges."

"My husband and I feel that parents of a child with special needs spend a lot of time soaking up information and taking strength and comfort from more experienced parents....Then one day we want to give back by supporting others."

"A lot of practical, everyday insights come from parents."

Parent to Parent of NH has been made possible with the support of:

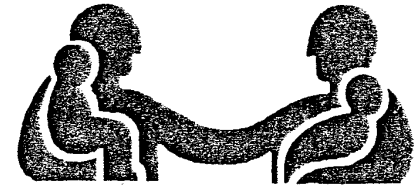
- ◆ The Upper Valley Support Group
- ◆ Bureau of Maternal and Child Health, US Department of Health and Human Services, SPRANS Project #MCJ335063-01
- ◆ NH Division of Public Health Services, Bureau of Special Medical Services
- ◆ NH Division of Mental Health: Child and Adolescence Service System Project (CASSP)
- ◆ Institute on Disability/UAP, Technology Partnership Project, University of New Hampshire
- ◆ The Jesse B. Cox Charitable Trust, Clinical Genetics and Child Development Center, Dartmouth Hitchcock Medical Center.
- ◆ The Lou And Lutz Smith Foundation of the NH Charitable Trust
- ◆ The New Hampshire Developmental Disabilities Council
- ◆ The Hood Center for Supporting Families:
 - Robert Wood Johnson Foundation, Partners in Health Project
 - RISC Take Charge Project
- ◆ Family Support Council, Region I
- ◆ Family Support Council, Region IV
- ◆ Family Support Council, Region V
- ◆ Family Support Council, Region VI
- ◆ Family Support Council, Region VII
- ◆ Family Support Council, Region XII



**PARENT TO PARENT
of New Hampshire**

PO Box 622
Hanover NH 03755
603-448-6393 or 1-800-698-LINK

Are you interested in being a trained supporting parent? Call Us.



Parent to Parent
of New Hampshire

-A Place to Start

1-800-



All Families Need Connections

Parents have one thing in common: they love to talk about their kids - what they're up to now, and expectations for the future. If you are the parent of a child with temporary or long-term special challenges, you may want to speak to a parent whose child has similar needs - someone who will understand. **Parent to Parent** is a statewide network of families willing to share experiences.



We believe that when parents are informed, connected and supported by other families **who have been there**, they are better able to define their needs and the needs of their children.

1-(800-)

698-LINK



Call Us. . .

- ① If your child has special medical, emotional, developmental or learning challenges.
- ② If you're looking for resources and services available in the state of New Hampshire.
- ③ If your child uses assistive technology (medical, educational, physical, recreational).
- ④ If you want to talk about any and all issues that you face as a parent.

Parents can be helped by other parents who have adjusted well to their own child's special challenges and have the capacity and willingness to help other parents by sharing their feelings and experiences, and by professionals who understand and believe in the elements of family centered care.



Affiliations:

Alliance for the Mentally Ill of New Hampshire (AMI)
Fragile-X Resource Center of Northern New England
Granite State Epilepsy Society
Institute on Disability
Karen's Climb (Cystic Fibrosis)
New Hampshire Challenge
New Hampshire Parents of Visually Impaired Children
New Hampshire Spina Bifida Association
Northern New England Down Syndrome Congress
Parent Participation Network of the Bureau of Special Medical Services
Parent to Parent of Concord
Parent to Parent of Greater Nashua
Parent to Parent of Keene
Parent to Parent of North Country Region I
Parent to Parent of Portsmouth
Parent to Parent of Region X
Parent to Parent of Strafford County
Turner Syndrome Society of Northern New England

Postage

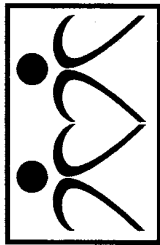
Our goal at
Parent to Parent

*is to give families
the skills and support
they need to help
their children with special needs
reach their full potential.*

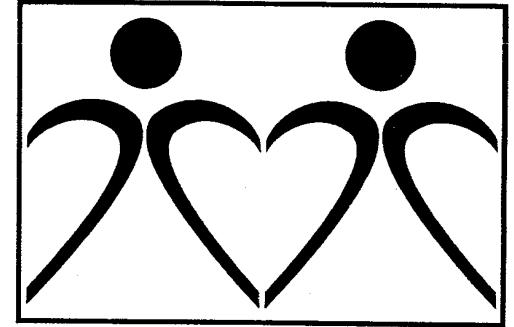
Our hope

*is for families
to feel less isolated and more confident
about themselves.*

All information is kept confidential.



New Jersey Statewide
Parent to Parent
35 Halsey St., 4th Floor
Newark, NJ 07102

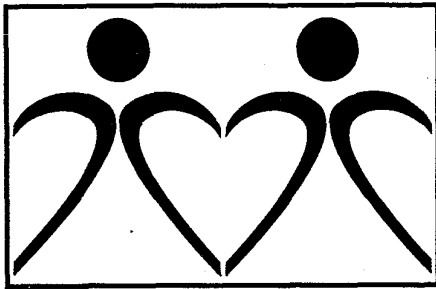


**New Jersey Statewide
Parent to Parent**

Parents Supporting Parents

1-800-FSC-NJ10
(1-800-372-6510)

Parents Supporting Parents



New Jersey Statewide Parent to Parent

Parent to Parent is a statewide network of parents supporting families of children with developmental delays, disabilities, or other special health needs.

As trained *supporting parents*, we offer emotional support and information, and act as a valuable resource to families. We offer assistance in learning the necessary skills to help parents face the challenges of raising their child.

We are not counselors or therapists. We are parents who have experienced the feelings and emotions that come after learning that our children have a developmental delay, disability, or other special health needs. We offer moral support and encourage parents to feel comfortable and optimistic about the future.

Parent to Parent is dedicated to supporting families at their most challenging times and to celebrating each new victory. Parents helping parents ... it's a simple concept that works.

What Parent to Parent Offers

- One-to-one matches of families who have similar needs and experiences.
- Emotional support for parents when they learn their child has a developmental delay, disability, or special health needs.
- Current information on a variety of disabilities and health issues.
- Training for parents who would like to become a *supporting parent*.
- Information on local, state, and national resources for the child and family.
- List of informative books on issues related to children with special needs.

All information is kept confidential.

If you would like to be matched with a supporting parent or would like to become a supporting parent, please complete and mail the form at right or call us at:

1-800-FSC-NJ10
(1-800-372-6510)

OUT OF STATE CALL 732-974-1144

New Jersey Statewide Parent to Parent

If you would like more information, please call us at 1-800-FSC-NJ10 or complete this form and mail it to:

Parent to Parent
c/o Statewide Parent Advocacy Network
35 Halsey St., 4th Floor
Newark, NJ 07102

Name _____

Address _____
Street

City _____ State _____ Zip _____

County _____

Telephone (____) _____
Area Code Phone Number

Please check all that apply:

- I would like to be matched with another parent.
- I am interested in becoming a supporting parent.
- I would like to receive more information on **Parent to Parent**.

*Parent to Parent is funded by
The NJ Department of Health and Senior Services
in cooperation with:*



and



WHAT DO WE DO?

- ♥ Match parents, foster parents, and adoptive parents of children and adults with special needs on a one-to-one basis according to need, whatever that need may be!
- ♥ Help parents or family members locate a support group that meets their needs.
- ♥ Provide technical assistance to local support and mentor groups.
- ♥ Assist and encourage the establishment of new local support or mentor groups.

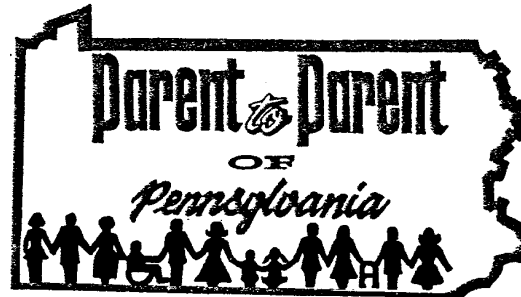
We are currently planning our expansion to include:

- ♥ matching grandparents, siblings, relatives, and children/adults with special needs to one another.
- ♥ matching neighbors, friends and others looking for ways to include someone with special needs in their lives.

WHAT IS OUR MISSION?



Parent to Parent of Pennsylvania is a network created by families for families of children and adults with special needs. We connect families in similar situations with one another so that they may share experiences, offer practical information and/or support.



1-800-986-4550

All services are free and confidential.

WHAT CAN WE DO FOR LOCAL SUPPORT GROUPS OR MENTOR GROUPS?

- ♥ connect your support group with other support groups in Pennsylvania
- ♥ refer parents to your group for purposes of becoming a member or being matched with one of your parent mentors
- ♥ provide you with material and information regarding
 - ~ funding possibilities
 - ~ training material for your parent mentors
 - ~ possible trainers or speakers for your meetings
- ♥ assist you in finding solutions for problems your group may be experiencing

Parent to Parent of Pennsylvania wishes to thank the Departments of Health, Education, and Public Welfare for funding us . . . and for supporting our mission!

**The Family Partner Program
of Family Connection**
funded through BabyNet

A Family Partner is available in every health district of South Carolina to assist families in finding information and resources, and to provide a listening ear. Family Partners help families understand the Individualized Family Service Plan (IFSP). They provide support and assurance in communicating with service providers, the medical community and other professionals. They understand and encourage parents to realize that as parents, they are their child's first and best teacher.

Family Partners are parents of children with special needs who are trained to provide help to families whose child or children have developmental delay and are eligible for services through BabyNet, South Carolina's early intervention program for infants and toddlers up to age three. This early intervention program is designed to help young children reach their potential and readiness for pre-school.

To find a Family Partner, call Family Connection at 252-0914 or toll free 1-800-578-8750.

To find out more about BabyNet, call toll free 1-800-922-1107.

There is no charge for programs of Family Connection.

Design, printing, and photography donated by friends of Family Connection.



Regular
Letter
Stamp
Here

Family Connection of South Carolina, Inc.
2712 Middleburg Drive, Suite 103-B
Columbia, SC 29204

**“If Your Child Has
Special Needs—
So Do You.”**



Family Connection of South Carolina, Inc.
a support network for families that have children with special needs

You Are Not Alone. Family Connection Can Help.

What Is Family Connection?

- Family Connection is a statewide organization of parents helping parents of children with disabilities, developmental delays, and chronic illnesses. Some of these children have Down syndrome, seizure disorders, cerebral palsy, and heart disease, but help is not limited only to these groups. Family Connection establishes parent networks wherever there is a need.

The group was started in 1990, and has grown to include hundreds of parents, grandparents, and siblings who provide emotional support and understanding to each other.

How Can Family Connection Help?

We offer you free, confidential services like:

- Parent-to-Parent Support
- Support Groups
- Family Social Events
- Workshops
- Newsletters
- Information



When Can Family Connection Help?

There are many times you may need support:

- At birth or time of diagnosis
- When dealing with educational concerns
- When illness strikes
- When planning for your child's adult years
- When you're concerned about brothers and sisters
- When dealing with day-to-day matters
- When you're new to the community
- Whenever we can help.



Why Should I Ask Family Connection for Help?

As a parent like you, we can talk about the joy as well as the pain of having a child with special needs. We can't offer any magic solutions, but we are willing to help.

How Can I Reach Family Connection?

Call us at 252-0914 in Columbia. Or you may visit our office at 2712 Middleburg Drive, Suite 103-B. Call today. Another parent is waiting to talk with you.

Make the Family Connection!

Please check those that apply to you, detach and mail today, or call 252-0914 for additional information about **Family Connection**.

I would like more information about **Family Connection**.

I would like to become a **Family Connection** volunteer.

I would like to be contacted by another parent through **Family Connection**.

I would like to be placed on the mailing list for **Family Connection**.

NAME _____

ADDRESS _____

CITY _____ STATE _____ ZIP _____

HOME PHONE _____ WORK PHONE _____

Philosophy and Goals

Parent to Parent of Virginia believes in the innate strength of most families. Therefore, we have a philosophy that our services should affirm parents' strengths and enable parents to obtain for themselves the services and supports their families need. We believe that professionals can give a family direction and ideas, but in order for families to become empowered, they need to be confident to explore and discover their own personal strengths.

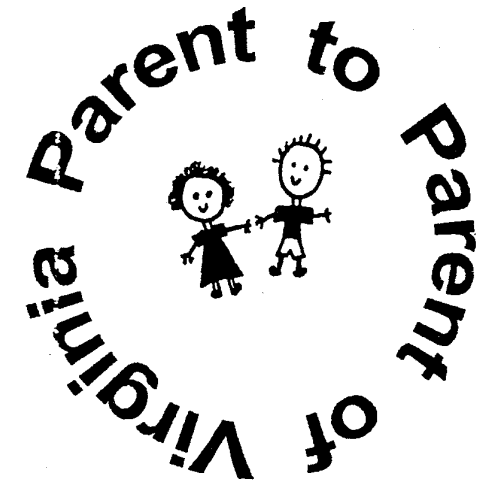
Parents need support from other parents so that they can carry on with their lives. To sit back and pity a family doesn't help them to help themselves. The best we can offer parents is positive self-esteem, pride in themselves and in their families, and the ability to seek the services they need.

Parent to Parent contact can help families regain their sense of strength, of purpose, and of independence.

Through it's network of volunteers, Parent to Parent can offer

- emotional support and understanding;
- coping skills and a model of positive family integration of children with special needs;
- information about services, support programs and advocacy organizations;
- introduction and access to people and groups who share their concern and interests and who can help them meet their needs, as well as those of their children.

Parent to Parent of Virginia
c/o The Arc of Virginia
6 North Sixth Street, #403-A
Richmond, Virginia 23219



Are you a parent of a child
with a disability or chronic
illness? If so, you are not
alone...

(804) 222-1945

or

(888) 604-2677

BEEN THERE.....

Parent to Parent of Virginia is a support parent network. We are parents, just like you, with children with:

- ♥ Cerebral Palsy
- ♥ Wolfe-Hirshhorn
- ♥ ADHD / ADD
- ♥ Tourette Syndrome
- ♥ Autism
- ♥ Speech Delay
- ♥ Down Syndrome
- ♥ Cystic Fibrosis
- ♥ Premature Birth
- ♥ Visual Impairment
- ♥ Leukemia
- ♥ Development Delay

Parent to Parent trains "veteran" parents who have "been there" to offer parents just learning of their child's diagnosis empathy, support and insight into parenting a child with special needs. Let us sit next to you on the roller coaster. You may find the ride is not as frightening as you imagined.

DONE THAT....



There I was, riding a roller coaster I didn't remember buying a ticket for. I was told my daughter has Cerebral Palsy, told to strap in and hold on. Clink, clank, up the first hill I started. "Get me off this ride!" I shouted. "I don't want a child that is disabled." As I came down the first hill, I not only lost my stomach but my dreams for my daughter's future as well. As the ride whipped me about I closed my eyes and felt shock, anguish, fear and anger overwhelming me. When I got the courage to open my eyes, I realized there was someone in the seat next to me - another parent with a child with special needs. She said, "Hold my hand and I will help you get through this ride." With my parent partners support, I learned that I was not the only one on this roller coaster. She listened to my fears and began to show me how to survive this ride and the others I would face. As we exited the roller coaster hand-in-hand, I knew that for now I would be okay and that she would strap in next to me the next time I got on the roller coaster.



Parents of young children with disabilities or chronic illness need extra support. The parents may feel ashamed, guilty, or different from other people because they have a child with special needs. These feelings can isolate them from their family, friends, and community when they need their support the most.

To learn more information about Parent to Parent of Virginia, to be matched with a 'partner,' or to become a volunteer parent partner for the program in your area, call:

(888) 604-2677

If you are interested in becoming a part of our network, please fill in the following information and send to: Parent to Parent of PA, 150 South Progress Avenue, Harrisburg, PA 17109 or Fax to: 717-540-7603.

Name _____

Address _____

County _____

Phone Number _____

When is the best time for us to contact you? _____



Call Toll Free
1-800-986-4550
TDD # 717-540-4722

Kathy Brill, Program Director
150 S. Progress Avenue, Harrisburg, PA 17109
717-540-4722
Fax 717-540-7603



<http://www.nauticom.net/www/eita>

Linking families and friends
of children and adults
with special needs.

1-800-986-4550
TDD # 717-540-4722

APPENDIX G

Parent to Parent Efficacy Study – Information and Results

NATIONAL STUDY OF PARENT TO PARENT: A SUMMARY OF THE RESULTS

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 a 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. There are over 500 local Parent to Parent programs nationally, with at least one program in every state, and approximately 35,000 parents are involved in one-to-one Parent to Parent matches.

A participatory action research team of parents and researchers completed a 3-year national study to determine the effectiveness of Parent to Parent support for referred parents. Parents and researchers from Parent to Parent of New Hampshire, Parent to Parent of Vermont, and the Hood Center at the Dartmouth-Hitchcock Medical Center; the Family Support Network of North Carolina and the University of North Carolina; the Family Connection in South Carolina; and Families Together/Parent to Parent of Kansas and the Beach Center on Families and Disability at the University of Kansas Parents worked together to design the study, write the grant application; and carry out this important study. Between 1994 and 1996, 400 referred parents in New Hampshire, Vermont, North Carolina, South Carolina, and Kansas participated in this study. Dr. George Singer, now at the University of California at Santa Barbara, CA directed this study.

WHY WE DID THIS RESEARCH

While parents know so well the real value of one-to-one Parent to Parent support, there were no research data to support these parent testimonials about the efficacy of Parent to Parent. Parent to Parent programs asked for research to determine the effectiveness of Parent to Parent support. Leaders in Parent to Parent believed that if data were available that demonstrated the effectiveness of Parent to Parent support, such data would enhance the credibility and fundability of Parent to Parent programs and the services they provide to parents who have a child/adult with a disability.

HOW OUR STUDY WORKED

A research team of parents and researchers in each of the five states recruited parents who have a son or daughter with special needs and who have never been in a Parent to Parent program to join the study. We distributed brochures announcing the study, printed articles in newsletters for parents who have a child with special needs, and informed service providers about the study. Parents chose to return a reply card to indicate their interest in the study, or they called an 800 number to talk to the research assistant. During the first contact with interested parents, the research assistant explained the study to the parents and asked them if they were willing to participate in an experiment that might require them to wait for 8 weeks before being matched with a veteran parent. No parent who was uncomfortable waiting was enrolled in the study. Parents who chose to enroll in the study were then randomly assigned to either the "No Wait" group or the "Wait" group.

Referred parents in the "No Wait" group were matched within 48 hours with a veteran parent who had had at least eight hours of training from a Parent to Parent program. Each of the referred parents received at least two face-to-face or telephone contacts during the first eight weeks of their match. Referred parents in the "Wait" group received no services from the Parent to Parent program for eight weeks. At eight weeks each of these parents was then matched with a veteran parent who had had at least eight hours of training. Parents in both groups were asked to fill out a set of questionnaires four different times during the study:

- Before randomization, as a pre-test
- At three weeks after randomization
- At two months after randomization
- At six months after being matched

The questionnaires allowed us to look for differences over the eight week time period when some parents were matched and some were not. We looked for differences in several different areas:

- Coping
- Acceptance
- Family empowerment
- Social support
- Reliable Alliance
- How much progress parents felt they made in getting their needs met

We will also conducted 24 telephone interviews, using ;a standardized interview protocol, with parents – 12 parents who reported that Parent to Parent was helpful and 12 who reported that Parent to Parent was not helpful.

After we collected all of the quantitative and qualitative data, we then entered the data into the computer and analyzed the data so that we could learn more about the impact of 1-1 Parent to Parent support on referred parents. We have shared our findings with families, with Parent to Parent programs, and with others interested in Parent to Parent support.

WHAT WE LEARNED FROM PARENT RESPONSES TO OUR QUESTIONNAIRES

About The Parents Who Participated in the Study

While we had 168 parents who enrolled in our study, not all of these parents actually completed the study by returning all of their questionnaires. Because we wanted to look for differences in the parent responses to our questionnaires from those parents who were involved in a one-to-one match during an eight-week time period and those parents who were not yet matched during this same eight-week time period, we used only the data from those parents who completed and returned all of the questionnaires during this eight-week time period. Thus, the total number of parents included in our data analyses was 128. Of these 128 parents, 8 or 6.3% lived in Vermont; 56 or 43.8% lived in New Hampshire; 36 or 28.1 % lived in North Carolina; 15 or 11.7% lived in South Carolina; and 13 or 10.2% lived in Kansas.

The vast majority of our responding parents were mothers (96%) with only 1 % of the parents being fathers, and 3% being another type. of caregiver (e.g., grandparent, aunt). Approximately 83% of the responding parents were Caucasian, with 13% African-American, .6% Native American, and 3% reporting Other. Most of the responding parents were married (65%), while 18% were divorced, 11% separated, 3% never married, and 2% widowed. Household annual incomes were reported to be over \$35,000 by 32% of the parents, with 68% reporting an annual income of less than \$35,000.

About the Children with Disabilities

The age of the child with a disability was reported to be five years or younger by 41% of the parents, between 6 and 11 years by 38% of the parents, and older than 12 years by 21% of the parents. The disabilities of the children of the parents participating in our study were described as follows (parents may have mentioned more than one disability, so %'s will not equal 100%):

Type of Disability	% of Parents Reporting
Developmental Delay	54%
Learning Disability	37%
Physical Disability	18%
Mental Retardation	17%
Visual Impairment	15%
Chronic Illness	12%
Cerebral Palsy	11%
Epilepsy	10%
Hearing Impairment	8%
Unknown	3%

Parents also indicated the level of severity of their child's disability, with 36% describing the disability as severe, 40% indicating that the disability was moderate, and 18% characterizing the disability as mild. For 6% of the parents, the severity of the disability was unknown.

The majority of parents had known about their child's diagnosis for more than 2 years (65%), with 24% knowing about the diagnosis for between one and two years, and 11% knowing about the diagnosis for less than one year.

About the Impact of Parent to Parent Support On Parental Acceptance

We used the Source of Strength and Family Closeness Subscale of the Kansas Inventory of Parental Perceptions (KIPP) to measure attitudes about a child with a disability in the family. This subscale consists of seven items about acceptance and perceptions of family adjustment.

Our data from the KIPP show that parents who participated in a Parent to Parent match demonstrated a significant gain on this measure of acceptance of family. and disability. There is a significantly larger increase in the mean scores of the parents in the Go Group who were matched in a one-to-one match with a supporting parent during the eight-week period compared to the mean scores of the parents in the Wait Group who waited during the eight-week period and were not matched.

When we look at the means scores of parents in both the Go and the Wait groups together before their matches and after they had all had the eight-week matched experience, we find that participation in a Parent to Parent match resulted in a statistically significant increase in parental acceptance.

About the Impact of Parent to Parent Support on Parental Coping

We used the Perception of Coping Efficacy Scale (PCES) to measure how parents felt they were coping with their child and their families. This questionnaire consists of 24 items which ask parents to report on how they felt during the past week about their capacity to cope with their child with a disability and their family.

Our data from the PCES show that parents who participated in a Parent to Parent match demonstrated some gain on this measure. While the increase in the mean scores of parents in the Go Group who were matched in a one-to-one match with a supporting parent during the eight-week period compared to the change in the mean scores of the parents in the Wait Group who waited during the eight-week period and were not matched is not statistically significant, the data indicate that Parent to Parent support does have some impact on parental coping.

When we look at the means scores of parents in both the Go and the Wait groups together before their matches and after they had all had the eight-week matched experience, we find that participation in a Parent to Parent match resulted in a statistically significant increase in how well the parents felt they were coping.

About the Impact of Parent to Parent Support on Family Empowerment

We used the Family Empowerment Scale (FES) to measure the parents' sense of being empowered. This scale consists of 31 items that measure how empowered parents feel with respect to their family, the service system, and their community.

Our data from the FES show that parents who participated in a Parent to Parent match demonstrated a detectable gain in parental perceptions of empowerment. While the increase in the mean scores of parents in the Go Group who were matched in a one-to-one match with a supporting parent during the eight-week period compared to the change in the mean scores of the parents in the Wait Group who waited during the eight-week period and were not matched is not statistically significant, the data indicate that Parent to Parent support does have some impact on parental sense of empowerment.

When we look at the means scores of parents in both the Go and the Wait groups together before their matches and after they had all had the eight-week matched experience, we find that participation in a Parent to Parent match resulted in a statistically significant increase in how empowered the parents felt they were.

About the Impact of Parent to Parent on Reliable Alliance

We used the Reliable Alliance Inventory (RAI) to measure the parents' sense of having a reliable ally. This scale consists of 24 items that measure how connected parents feel to someone with a similar set of experiences to their own.

Our data from the RAI show that there were no significant differences in the mean scores of parents in the Go Group who were matched in a one-to-one match with a supporting parent during the eight-week period and the mean scores of the parents in the Wait Group who waited during the eight-week period and were not matched.

When we look at the means scores of parents in both the Go and the Wait groups together before their matches and after they had all had the eight-week matched experience, we find that participation in a Parent to Parent match resulted in a statistically significant increase in the parents' sense of having a reliable ally.

About the Impact of Parent to Parent on Social Support

We used the Social Provisions Scale (SPS) to measure the parents' sense of being socially connected with others. This scale consists of 24 items that measure how connected parents feel to others.

Our data from the SPS show that there were no significant differences in the mean scores of parents in the Go Group who were matched in a one-to-one match with a supporting parent during the eight-week period and the mean scores of the parents in the Wait Group who waited during the eight-week period and were not matched.

When we look at the means scores of parents in both the Go and the Wait groups together before their matches and after they had all had the eight-week matched experience, we find that

participation in a Parent to Parent match did not result in a statistically significant increase in the parents' sense of social support.

About the Progress Parents Felt They Made on Having Their Needs Met

In order to measure whether or not parents felt they had made progress on the specific problem that parents wanted Parent to Parent to address, we asked parents to respond to two questions. The first asked them to identify their major specific need that influenced them to seek Parent to Parent support. The second asked them how much progress they felt they had made in getting that need met.

Our data show that parents who participated in a Parent to Parent match reported that they made significantly greater progress on getting their needs met than parents who did not participate in a Parent to Parent match

About the Impact of Parent to Parent on Level of Stress

In order to learn more about the levels of stress related to the child of parents before and after their matched experience, we asked parents to describe their level of stress.

Our data show that parents who participated in a Parent to Parent match and those parents who were not yet matched both showed some reduction in stress related to the child over the course of the study, but the differences between the parents who were matched and the parents who were not yet matched were not significant.

When we look at both groups of parents together before their match and after their eight-week matched experience, we find that participation in a Parent to Parent match did not result in a statistically significant decrease in the parents' stress related to the child with a disability.

The fact that we found no significant differences in the levels of stress related to the child as a result of Parent to Parent support may be because a Parent to Parent match offers parents emotional support and information, but it cannot change (at least immediately) many of the system stressors (e.g., medical and financial realities) that families continue to face.

About the Impact of Parent to Parent on How Helpful Parents Perceive Parent to Parent to Be

At the end of their eight-week matched experience, we asked each parent to tell us how helpful Parent to Parent had been to them. When we look at both groups of parents together after their eight-week matched experience, our data show that for all the parents who participated in an eight-week Parent to Parent match, 80% reported that Parent to Parent was at least slightly helpful.

About the Services Learned About Because of Parent to Parent

We provided parents with a list of 39 common kinds of support that parents typically request when they call Parent to Parent. We used this list to develop a questionnaire that asked parents to respond to the double question: *Which of the following services does your child currently*

receive? and Which of these services did you learn about from Parent to Parent?

Our data indicate that a Parent to Parent match provided parents with new information about available services for only a minority (approximately 15%) of the parents. Perhaps this finding is an indication that the service system as a whole is providing parents with more information about available services and so parents are as a whole better informed.

About the Number of Contacts in the Match

We were also interested in learning about how many contacts occurred between the supporting parent and the referred parent during the eight-week matched period of the study. At the end of the eight-week matched experience for parents in both the Go Group and the Wait Group, we asked them to report on the number of contacts they had with their matched parent.

Our data revealed that for most parents the Parent to Parent match consisted of only a few contacts during the eight-week matched period of the study, with the average number of contacts during the eight-week match being 2.84.

About the Effect of the Number of Contacts on How Helpful Parents Perceived Parent to Parent to Be

In order to determine if there was a relationship between the number of contacts in a match and how helpful the referred parents found Parent to Parent support to be, we looked at the combined responses from the Go Group and the Wait Group parents at the end of their eight-week matched experiences. Our data clearly suggest that the more contacts there are between the matched parents, the more helpful Parent to Parent support is found to be.

WHAT WE LEARNED FROM OUR CONVERSATIONS WITH PARENTS

We randomly selected 24 parents who had completed the study (12 of whom found Parent to Parent support to be helpful and 12 of whom found Parent to Parent support not helpful): All 24 were biological parents, with 23 being mothers, and one father.

The 12 parents we talked with who found Parent to Parent to be helpful told us that Parent to Parent was helpful to them because:

- The supporting parent had family and disability experiences that were similar to their own. These 12 parents could tell that the supporting parent had *been there and walked in the same shoes*. One parent commented:

It was a very helpful experience from the perspective that you realize that you're not alone, dealing with the problems; that you have someone there who ... has similar experiences...

- They could compare the reactions of the supporting parent to the disability experience and find that they were similar to their own and that their own feelings were normal. They also mentioned that being able to see what life

was like for the supporting parent gave them a greater sense of hope for the future for their child and family. A parent explained:

It really did help to know that some of the things we were thinking and feeling were perfectly normal; that there wasn't anything with it.

- Their supporting parent was available 'round the clock – just a telephone call away. Even if they didn't talk to the supporting parent all that often, they knew that they could at any time. A parent commented:

If I didn't feel confident in going to someone else, I knew that I could always pick up the phone and call my support parent and discuss some things with her.

- The relationship between the referred parent and the supporting parent is an equal one based upon similar life experiences, and the support is often reciprocal. One parent related:

She just tries to help me out.... If she is having a bad day, I'll try to help her out.... We just take turns calling each other checking up....

The 12 parents we talked with who found Parent to Parent to be not as helpful told us that Parent to Parent was not as helpful to them because:

- Their child's disability and/or their family's situation was so rare that an appropriate match could not be found. The Parent to Parent program did not have a supporting parent with similar experiences who was available to be a part of a match.
- The busy lives that most parents of children with disabilities lead sometimes means that frequent contact is difficult. One parent reported that she had been matched with a supporting parent who lived in a different part of the state. The long distance telephone expenses meant that contacts had to be brief and infrequent. She explained:

Because I know we would have kept even more in touch if that hadn't been a problem..., we couldn't talk that long because of the cost.

- The supporting parent's family and disability situation is too different from their own. While Parent to Parent programs try to make the closest possible match, a supporting parent with exactly the same family and disability experiences may not always be available. One parent elaborated:

I mean we have similarities, but they're still different in the disabilities It's helpful to learn what they went through [with] some of the problems. But then there are some that come up that... she hadn't experienced.

- The supporting parent's personality and style are too different from their own – communication style, parenting style, outlook on disability, future vision for the child. A parent related:

We have different styles of dealing with our children and we realized that very quickly. .. She has a very different way of looking at things ... her point of view about things is different.

HOW THIS INFORMATION CAN BE HELPFUL

As a Basis for Justifying the Importance of Parent to Parent Support

For the last 20+ years, parents have been appreciating the value of Parent to Parent support and many have shared their experiences in a Parent to Parent match in an anecdotal way.

Now there are *hard* data that have been generated from this study that support what parents have been saying for years. These data, when added to the parent testimonials, may be very useful in convincing funding sources and policymakers about the effectiveness of Parent to Parent support. Perhaps the results of our study will mean that more Parent to Parent programs will be available for families, and that Parent to Parent support will become an integral part of a comprehensive system of services for families.

Referral sources to Parent to Parent programs (e.g., medical professionals, social workers, teachers, religious leaders, other parents) are an important link to the success of a Parent to Parent program. As these referral sources learn about the existence of data that demonstrate the effectiveness of Parent to Parent support, they may refer parents to Parent to Parent programs with greater frequency.

As a Basis for Programmatic Information for Parent to Parent Programs

The results from our quantitative study clearly demonstrate that Parent to Parent makes a significant difference in parents' acceptance, their sense of being able to cope, and the progress that parents feel they make on the need or problem that existed when they contact a Parent to Parent program. From our qualitative study, our interviews with parents suggest some programmatic best practices that Parent to Parent programs may want to consider adding to or expanding in their own programs:

- Parent to Parent coordinators should take time to learn about the referred parent's needs, personality, and preferences before making a match.
- Parent to Parent coordinators should make follow-up calls to both parents in a match to ensure that the connection has been made and that the match is a positive experience for both parents.
- Referred parents and supporting parents need to understand that a re-match is always an option.
- Supporting parents should be responsible for initiating and maintaining contacts with the referred parents.
- Supporting parents should be aware that the more contacts a referred parent has from a supporting parent, the more helpful the referred parent finds Parent to Parent to be.
- Additional funding is necessary so that long distance telephone expenses

related to the match do not have to be incurred by the parents.

As a Basis for New Resources for Families and Professionals

Parent to Parent programs have been seeking ways to evaluate their own program effectiveness, and the procedures and questionnaires that were used in our study provide a tailor-made way to evaluate Parent to Parent programs. Our team developed the ***Parent to Parent Program Evaluation Manual*** that provides step-by-step procedures and sample forms for Parent to Parent programs to use in conducting their own program evaluation.