

Section VII

Developing and Expanding a Statewide Parent to Parent Program

2000

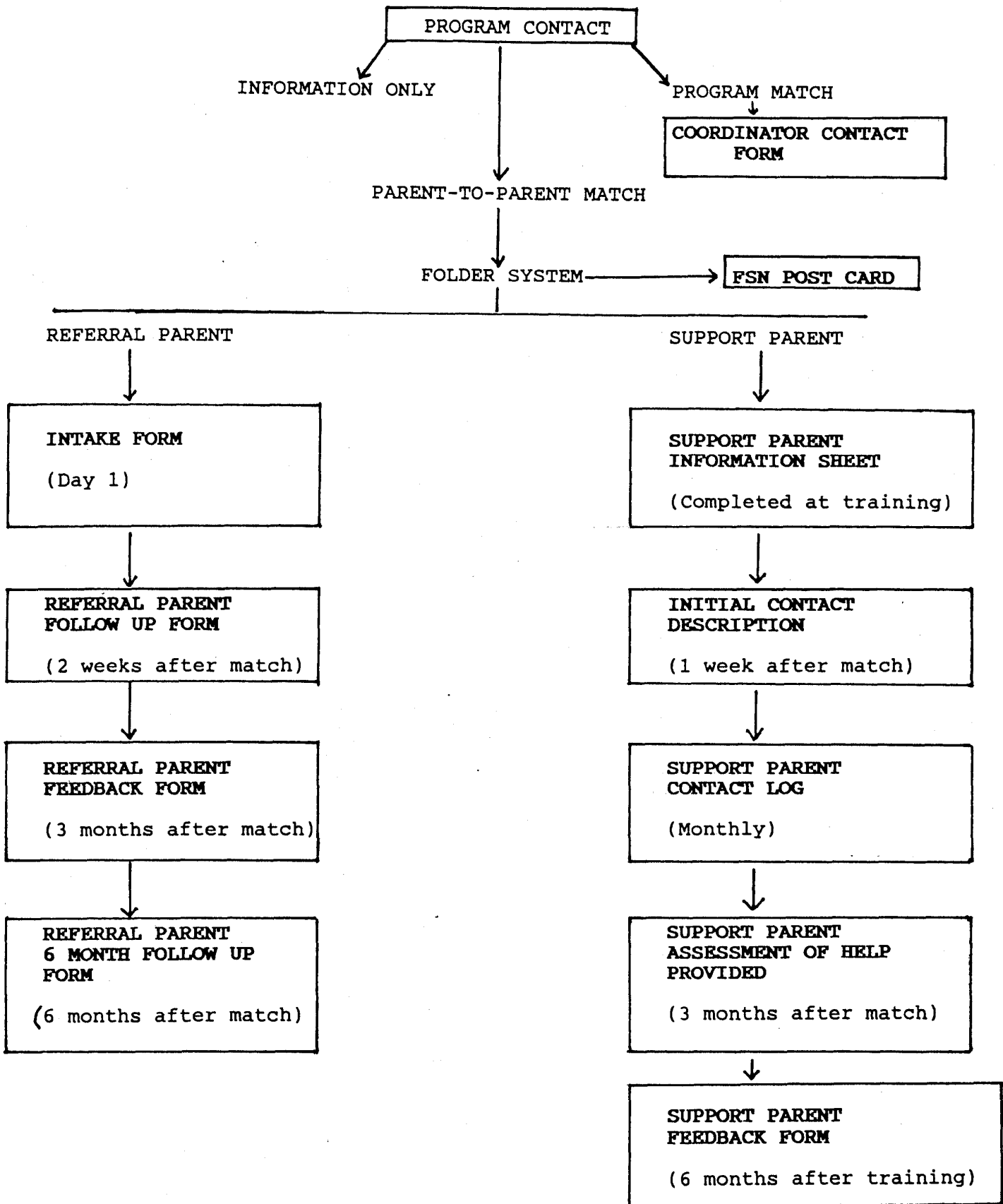
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APPENDIX H

Sample Forms for Documenting the Match and its Process

FLOW CHART OF FOLDER SYSTEM



INTAKE FORM

Timing: at referral
Sent to FSN? ___

Date: ___/___/___
Family Member: _____
(mother, father, couple)

Referral Parent ID# ___ ___ ___ Support Parent ID# ___ ___ ___

Type of parent: ___ 1. Support County of Residence: _____
 ___ 2. Referral Community: _____

Date of initial referral: ___/___/___ Date of Match ___/___/___

Did a third party contact the program about the family? ___ yes ___ no

If yes, describe the third party (type of professional, support parent, etc.) _____

If no, ask the parent:
How did you hear about the parent-to-parent program?

- ___ 1. Brochure ___ 5. Another parent ___ 7. Teacher/Educ. Program
- ___ 2. TV ___ 6. Medical doctor ___ 8. Mental Health worker
- ___ 3. Newspaper ___ 7. Speech therapist ___ 9. Clergy/minister
- ___ 4. Radio ___ 8. PT ___ 10. Social worker
- ___ 11. Other professional (specify) _____
- ___ 12. Other source (specify) _____

If professional, with what agency is the professional associated?

FAMILY DESCRIPTION:

Race:
___ 1. White
___ 2. Black
___ 3. Other (specify): _____

Religious Preference:
___ 1. Protestant
___ 2. Catholic
___ 3. Jewish
___ 4. Other (specify): _____
___ 9. Unknown

Marital status:
___ 1. Married
___ 2. Separated/Divorced
___ 3. Widowed
___ 4. Single

Mother's Age:
___ 1. Under 25
___ 2. 25-40
___ 3. 41-59
___ 4. 60+

INTAKE FORM (pg. 2)

Mother's Education:

- 1. Less than high school
- 2. High school graduate
- 3. College graduate
- 4. Postgraduate degree (MD, PhD, MA, MS, etc.)
- 5. Other (specify) _____
- 9. Unknown

Educational/Training Area _____

Mother's Occupation: _____

Father's Age:

- 1. Under 25
- 2. 25-40
- 3. 41-59
- 4. 60+

Father's Education:

- 1. Less than high school
- 2. High school graduate
- 3. College graduate
- 4. Postgraduate degree (MD, PhD, MA, MS, etc.)
- 5. Other (specify) _____
- 9. Unknown

Educational/Training Area _____

Father's Occupation: _____

Do both mother and father live with the child in the home?
 yes; no, mother only; no, father only

Did the family mention other adults living in the home?
 yes (specify _____) no

Does the child have older siblings? brothers sisters
Does the child have younger siblings? brothers sisters

INTAKE FORM (pg. 3)

CHILD'S DESCRIPTION: (If more than one special needs child, complete pg. 3 for each child.)

Child Name: _____

Child Gender: ____ boy ____ girl

Birthdate: ____/____/____

Special Needs of Child (Include diagnoses if appropriate, special circumstances of birth, child death, etc.):

When learned of child's special need: ____/____ (month, year)

Services Currently Received (Educational, Nutritional, Financial, Medical)

School placement (e.g., Developmental daycare, regular class with resource, full time special class, etc.):

Work placement (e.g., Sheltered workshop, etc.):

Alternative Living Arrangement (e.g., Group home, etc.):

INTAKE FORM (pg. 4)

MATCH PREFERENCE:

What did the family indicate as important in being matched with another family?

(parent of same age, race, education, religion, marital status, geographical area; child of same age, gender, special need)

OTHER RELEVANT INFORMATION:

Date: ___/___/___
FSN ___ (training)

Mom only ___
Dad only ___
Couple ___

SUPPORT PARENT INFORMATION SHEET

Please complete this form by answering the questions which you feel comfortable answering. This information will help us to match you with referral families and to document who our program is reaching.

How did you hear about the parent-to-parent program?

- | | | |
|--|---|--|
| <input type="checkbox"/> Brochure | <input type="checkbox"/> Another parent | <input type="checkbox"/> Teacher/Educ. Program |
| <input type="checkbox"/> TV | <input type="checkbox"/> Medical doctor | <input type="checkbox"/> Mental health worker |
| <input type="checkbox"/> Newspaper | <input type="checkbox"/> Speech therapist | <input type="checkbox"/> Clergy/minister |
| <input type="checkbox"/> Radio | <input type="checkbox"/> PT | <input type="checkbox"/> Social worker |
| <input type="checkbox"/> Other professional (please specify) _____ | | |
| <input type="checkbox"/> Other source (please specify) _____ | | |

If you heard about the program from a professional, with what agency or program is the professional associated?

Please complete the following information about your child with special needs:

Is your child a ___ boy or a ___ girl?

What is your child's birthdate? ___/___/___

Please describe the nature of your child's special need (Include special circumstances of birth, diagnoses of illness or disability, etc.)

When did you first learn of your child's special need? ___/___
(month, year)

What services is your child currently receiving? (For example, developmental daycare, speech therapy, physical therapy, etc.)

What is your child's school placement?

If adult, what kind of work setting/program is your son/daughter in?

Does your child live in a setting outside the home? If so, please specify. (For example, group home, institution, etc.)

Please list the ages of brothers and sisters of your child with special needs:

Brothers _____ Sisters _____

Please complete the following questions describing you and/or your family*:

*Mother and father refer to the mother and father of the child with special needs.

Race:

- White
- Black
- Other (please specify): _____

Religious Preference:

- Protestant
- Catholic
- Jewish
- Other (please specify): _____

Marital status:

- Married
- Separated/Divorced
- Widowed
- Single

Mother's Age:

- Under 25
- 25-40
- 41-59
- 60+

Mother's Education:

- Less than high school
- High school graduate
- College graduate
- Postgraduate degree (MD, PhD, MA, MS, etc.)

Mother's Occupation: _____

Father's Age:

- Under 25
- 25-40
- 41-59
- 60+

Father's Education:

- Less than high school
- High school graduate
- College graduate
- Postgraduate degree (MD, PhD, MA, MS, etc.)

Father's Occupation: _____

Please list other adults who live in your home (For example, grandmother, uncle, friend, etc.)

Please list other organizations or groups with whom you are involved (for example, ARC, LDA, Kiwanis, etc.).

Support Parents contribute to the program in a variety of ways. Please indicate which of the following activities are of interest to you.

- being matched with referred families
- attending parent meetings
- assisting with fund-raising
- assisting with program publicity
- assisting with office tasks including program newsletter
- others (please list)

NAME _____

DATE _____

Have you had experience with any of the following which you are willing to share or provide support in any of the following areas:

- | | |
|---|--|
| <input type="checkbox"/> Ankle - Foot Orthosis (AFO) | <input type="checkbox"/> Kidney Reflux |
| <input type="checkbox"/> Apnea | <input type="checkbox"/> Learning Disability |
| <input type="checkbox"/> Audio Sensitivity | <input type="checkbox"/> Microcephaly |
| <input type="checkbox"/> BabyNet | <input type="checkbox"/> Missing Limbs |
| <input type="checkbox"/> Bladder Catherization | <input type="checkbox"/> Neupogen Injections(G-CSF) |
| <input type="checkbox"/> Blindness | <input type="checkbox"/> NICU |
| <input type="checkbox"/> Bone Marrow Transplant (BMT) | <input type="checkbox"/> Out of State Surgery |
| <input type="checkbox"/> Brain Bleed | <input type="checkbox"/> Oxygen Therapy |
| <input type="checkbox"/> Bronchial Pulmonary Dysplasia(BPD) | <input type="checkbox"/> Radiation |
| <input type="checkbox"/> Broviac | <input type="checkbox"/> Reflux |
| <input type="checkbox"/> Cardiology | <input type="checkbox"/> Respiratory Distress (RDS) |
| <input type="checkbox"/> Chemotherapy | <input type="checkbox"/> Respite |
| <input type="checkbox"/> Childcare | <input type="checkbox"/> Paralysis |
| <input type="checkbox"/> Communication Devices (CMV) | <input type="checkbox"/> Prosthesis |
| <input type="checkbox"/> CRS | <input type="checkbox"/> Sibling Issues |
| <input type="checkbox"/> Death of a Child | <input type="checkbox"/> Sickle Cell Crisis |
| <input type="checkbox"/> Developmental Delays | <input type="checkbox"/> Seizures |
| <input type="checkbox"/> ECMO | <input type="checkbox"/> Sepsis |
| <input type="checkbox"/> Factor VIII Injection | <input type="checkbox"/> Shunt |
| <input type="checkbox"/> Failure to Thrive | <input type="checkbox"/> Speech Delay |
| <input type="checkbox"/> Gastrostomy | <input type="checkbox"/> Special Diet |
| <input type="checkbox"/> Genetic/Rare Disorder | <input type="checkbox"/> SSI |
| <input type="checkbox"/> G-Tube | <input type="checkbox"/> Steroid Side Effects |
| <input type="checkbox"/> Hair Loss | <input type="checkbox"/> Stroke |
| <input type="checkbox"/> Heart Monitor | <input type="checkbox"/> Tefra |
| <input type="checkbox"/> HIV | <input type="checkbox"/> Therapy |
| <input type="checkbox"/> Home Health | <input type="checkbox"/> OT |
| <input type="checkbox"/> Home Nursing Care | <input type="checkbox"/> PT |
| <input type="checkbox"/> Hospice | <input type="checkbox"/> Speech |
| <input type="checkbox"/> Hydrocephalus | <input type="checkbox"/> Thyroid |
| <input type="checkbox"/> IEP | <input type="checkbox"/> Tracheostomy |
| <input type="checkbox"/> IFSP | <input type="checkbox"/> Ventilator |
| <input type="checkbox"/> Immune Deficiency | <input type="checkbox"/> Venous Access Device (V.A.D.) |
| <input type="checkbox"/> Irritable Bowel/Bladder | <input type="checkbox"/> Wheelchair |

Timing: within 2 weeks after match

Sent to FSN? ___

Support Parent ID# ___ ___ ___

Date ___/___/___

Referral Parent ID# ___ ___ ___

Family Member: _____
(mother, father, couple)

INITIAL CONTACT DESCRIPTION

Date of Contact: ___/___/___

Length of Contact: _____ (minutes)

Type of Contact:

- ___ 1. phone
- ___ 2. person
- ___ 3. hospital

What were the major concerns that the parent(s) raised?

What (if any) other concerns did you perceive?

Did the parent(s) express an indication of the type of contact preferred?

- ___ 1. yes
- ___ 2. no

What was their preference?

- ___ 1. phone
- ___ 2. person
- ___ 3. other (explain): _____
- ___ 4. not applicable, no type preferred

How would you rate the receptiveness of the parent(s) to your call/contact?

- ___ 1. not receptive
- ___ 2. moderately receptive
- ___ 3. very receptive

Comments:

Plan of Action: List any materials or information to gather for him/her or any referrals to other community services and plan for future contacts.

Timing: 2 weeks after match

Sent to FSN? ___

Support Parent ID# ___ ___ ___ ___

Date: ___/___/___

Referral Parent ID# ___ ___ ___ ___

Family Member: _____
(mother, father, couple)

REFERRAL PARENT FOLLOW-UP FORM

(I am calling from "parent-to-parent program" and want to check and see that _____ has been able to reach you and to make sure things are going OK)
(Support Parent's name)

1. Has (Support Parent) contacted you? ___ Yes ___ No

2. (If yes) how are things going?

3. (If no) when are good times to reach you? Is there a problem? Is there anything I can do to facilitate the interaction?

(I'll be calling again in a few months to check about how things are going.....)

Timing: 3 months after referral

Sent to FSN? ____

Support Parent ID# ____

Date: ____/____/____

Referral Parent ID# ____

Family Member: _____
(mother, father, etc.)

REFERRAL PARENT FEEDBACK FORM

(To help us in evaluating our program we'd like to ask you some questions.)

1. In first getting involved with the program, Did you contact the program yourself ____ (1) or did someone give the program your name and they contacted you ____ (2) or don't remember ____ (3)?
2. How many days delay were there between when you initially requested involvement or were referred to parent-to-parent and were contacted by your support parent?

3. Some people feel comfortable initiating contact with the family they are matched with; others find that difficult. How did you feel about that?
4. How satisfied were/are you with the type and amount of contact you have had with the support parent?

1	2	3	4	5
Very Dissatisfied				Very Satisfied

Please explain:

5. What members of your family participated in parent-to-parent?

____ mother of child, ____ father of child,
 ____ others (please specify) _____

(If other family members are involved, ask here if it would be possible/desirable to talk with them as well about the program.)

(OVER)

REFERRAL PARENT ASSESSMENT FORM (pg. 2)

6. What were/are the most helpful aspects of participation in parent-to-parent?

7. What were/are the least helpful aspects of participation in parent-to-parent?

Please think about the time you have been involved in parent-to-parent. During this time parent-to-parent has helped me:

8. Increase the size of my support network of friends and family:

1	2	3	4	5
Not at All				A Great Deal

9. Understand more about my child's special need:

1	2	3	4	5
Not at All				A Great Deal

10. Share my feelings and concerns (given me someone to talk to who understands my problems):

1	2	3	4	5
Not at All				A Great Deal

11. Increase awareness of advocacy roles for my child (help my child obtain services that are rightfully his/hers):

1	2	3	4	5
Not at All				A Great Deal

REFERRAL PARENT ASSESSMENT FORM (pg. 3)

12. Utilize additional community resources:

1	2	3	4	5
Not at All				A Great Deal

13. What agencies or other services for your child have you contacted during this time that you were previously unaware of?

14. Do you feel the support parent you are/were matched with is/was a good match for you?

___ 1. yes ___ 2. no

Why or why not?

How could the match have been better?

15. Would you recommend parent-to-parent to others?

___ 1. yes ___ 2. no

16. What other suggestions/comments/observations do you have about the program?

(OVER)

Support Parent ID _____
Referral Parent ID _____

SUPPORT PARENT RECORD OF CONTACTS

Date	Type*	Initiator	Length	With Whom	Content	Follow-up needed/ Date when completed	Mileage	Misc. Exp.

*Type of Contact Codes: H.V. -home visit
Hosp. -hospital visit
T.C. -Telephone Call
L -Letter

Support Parent ID# ___ ___ ___
Referral Parent ID# ___ ___ ___

Date: ___/___/___
Family Member: 1
(mother, father, couple)

FSN ___ (3 months after match)

SUPPORT PARENT IMPRESSION OF HELP PROVIDED (pg. 1)

Check the ways in which you feel parent to parent may have helped the referral family:

- 1. Emotional support through listening
- 2. Information about services/equipment
- 3. Help in problem solving
- 4. Referral to a service or agency
- 5. Transportation
- 6. Child Care
- 7. Other (please specify) _____

Please think about the family you were matched with when answering these questions. Would you say this family:

1. Increased the size of their support network of friends and family:

- 1. None
- 2. A little
- 3. Moderately
- 4. A lot
- 5. Not sure

2. Understand more about their child's special need:

- 1. None
- 2. A little
- 3. Moderately
- 4. A lot
- 5. Not sure

3. Shared feelings and concerns with you:

- 1. None
- 2. A little
- 3. Moderately
- 4. A lot
- 5. Not sure

4. Increased awareness of advocacy roles for their child:

- 1. None
- 2. A little
- 3. Moderately
- 4. A lot
- 5. Not sure

5. Utilized additional community based resources:

- 1. None
- 2. A little
- 3. Moderately
- 4. A lot
- 5. Not sure

SUPPORT PARENT IMPRESSION OF HELP PROVIDED (pg. 2)

What other specific benefits did the referral family mention to you?

What other ways do you think involvement in parent-to-parent has been helpful to this family?

Did this family need assistance that the parent-to-parent program could not provide?

Parent to Parent of NH

THE REFERRAL/CONTACT PROCESS

About the referral/contact process:

This referral/contact process is unchanged in essence from how you have always been supporting families. The study requires 4 contacts by you as a Supporting Parent. Postcards indicating contact with families can be sent in to Parent to Parent as contacts are made. You may complete the 4 contacts within 2 weeks of your match or 4 contacts may take 2 months depending on the needs of the referred family.

1. When Parent to Parent calls you about a match, please say "No" if it isn't a good time for you and you cannot accept the referral. When you can accept a referral, contact the referred parent(s) within 24 hours by phone or in person.

Send postcard #1 to the Parent to Parent office, giving the date of your initial visit or phone call with the family.

Parent to Parent will be in contact with you after your initial call or visit to your referred parent to see if there is additional information or resources you may need for the family.

2. Make it clear that you are available to the family and let them know you will be in touch with them within the next two weeks. Of course, more frequent contact based on the family's need is encouraged.

Send postcard #2 to the Parent to Parent office with the date of your second contact.

3. Within one month of the initial contact, unless your relationship with the family has resulted in more frequent contact, call or visit your family a third time saying you were thinking about them and/or invite them to a parent activity or a presentation relative to their expressed interest.

Send postcard #3 to the Parent to Parent office after this phone call/visit.

4. Within one more month (8 weeks from your initial contact) get in touch with your referred parent again or continue responding to the family's need for support as necessary.

Send postcard #4 to the Parent to Parent office after this phone call/visit.

5. We encourage you to stay in touch with your referred family to let them know you are available if they find they would like to talk to you again. You might want to give them a call after six months or a year.



PARENT TO PARENT OF NH

SUPPORTING PARENT CONTACT RECORD

SUPPORTING PARENTS NAME _____

REFERRED PARENTS NAME _____

DATE YOU RECEIVED REFERRAL ____/____/____

LOCAL COORDINATOR'S NAME _____

COORDINATOR'S FIRST CONTACT W/ REFERRED PARENT ____/____/____

FOUR DATES CONTACTS WERE MADE WITH SUPPORTING PARENT:

1 ____/____/____ 2 ____/____/____ 3 ____/____/____ 4 ____/____/____

SITUATIONS THAT NEED TO BE FLAGGED

(PLEASE CHECK ALL THAT APPLY)

- _____ 1. **Un-trained supporting parent-** When the match is made with a supporting parent who has not received the 8 hours of training.
- _____ 2. **Double match-** When a precise match is not possible and the referred parent is matched with more than one support parent.
- _____ 3. **Re-match-** When the initial match must be changed for any reason and a re-match is made. Date of re-match: ____/____/____
- _____ 4. **Delay in match-** When there is a delay in making the actual match with the supporting parent, e.g. the parent receives the first contact from the P-P program (thus beginning our time clock) but then the local coordinator does not make a match within the usual 24-48 hours.
- _____ 5. **Long distance match-** (please explain) _____
- _____ 6. **Four contacts not made-** When the required 4 contacts do not occur during the 8 week period.
- _____ 7. **Couple match-** When the parent is participating as part of a couple.
- _____ 8. **Match made on the basis of:** Same diagnosis, age of child, similar issues, similar school district, socio economic, ethnic.

Parent to Parent
Phone Log For Supporting Parent

You just got a referral from a Parent to Parent Coordinator, you want to call as soon as possible, preferable in 24 hours. This form is to help you record information.

Date: _____ Parent's name seeking support: _____

Address: _____ Tel. # _____

Child's Name and age: _____

Situation/Reason for Contact:

- * Share your experiences.
- * Be POSITIVE, but realistic.
- * Ask Mom how she's doing (or Dad, siblings).
- * LISTEN
- * Encourage

Information request:

- * Remember your resource guide.
- * Need more info-give a coordinator a call.

Before you hang up, promise to call again.

Arrange time and day for next call.

- * How about a luncheon date?
- * Kids might like to get together.
- * Siblings may like to support each other.

Parent to Parent of VT

SUPPORTING PARENT FORM

Supporting Parent Name: _____

Referred Family: _____

Date of Referral: _____

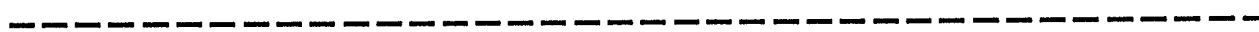
Follow-up on Match
Dates of Contact/Comments

#1 _____

#2 _____

#3 _____

#4 _____



Referred Family: _____

Date of Referral: _____

Follow-up on Match
Dates of Contact/Comments

#1 _____

#2 _____

#3 _____

#4 _____

Parent to Parent of VT

POSTCARD RESPONSES

<p style="text-align: right;">1st</p> <p>I have contacted my referred parent.</p> <p>Date _____</p> <p>Signed _____</p>	<p style="text-align: right;">2nd</p> <p>It has been two weeks and I have contacted my referred parent.</p> <p>Date _____</p> <p>Signed _____</p>
<p style="text-align: right;">3rd</p> <p>It has been one month and, yes, I have talked/visited with my referred parent.</p> <p>Date _____</p> <p>Signed _____</p>	<p style="text-align: right;">4th</p> <p>Within this second month, I have contacted my referred parent again.</p> <p>Date _____</p> <p>Signed _____</p>

E. Sample - Referred Parent Information Form

Referred Family Information Form

Referred by: _____ Phone # _____

1. Sent information packet (date) _____
2. First contact with family (date) _____
3. Match - if requested (date) _____
Supporting Parent's Name _____
Trained _____ Untrained _____
4. Follow up with Supporting Parent (date) _____
5. Supporting Parent contacts: within 24 hours _____ within 2 weeks _____
within 1 month _____ within 2 months _____

1. FAMILY

Name _____

Address _____

Phone _____ Place of Employment _____

Interests/Hobbies _____

Marital Status: ___ Married ___ Divorced ___ Separated ___ Single ___ Widowed

Partner's Name: _____

Occupation _____

Name of Each Child	Date of Birth	Sex
--------------------	---------------	-----

_____	_____	_____
-------	-------	-------

_____	_____	_____
-------	-------	-------

_____	_____	_____
-------	-------	-------

E. Sample - Referred Parent Information Form, continued

2. CHILD WITH DISABILITY

Name _____

Primary Diagnosis _____

Other Diagnosis, limitations or symptoms _____

Was disability known from birth? ___ Yes ___ No

If not, since when? _____

3. SPECIAL CONCERNS OF PARENTS:



REFERRED PERSON INFORMATION

Yes, I am looking for a match!

If you would like to be matched to another person, who was once in a similar situation (to share experiences, information, and advice), please completely fill out both sides of this form and return it to your regional or statewide Parent to Parent of Pennsylvania office. **We will find a match for you as quickly as possible. All information will be highly confidential.**

Return to:
 Parent to Parent of PA
 150 South Progress Avenue
 Harrisburg, PA 17109

Today's date: _____

Name: First _____ Middle _____ Last _____

Address: Street _____
 City _____ State _____ Zip _____ County _____

Telephone Numbers:
 Home (____) _____ Work (only if you can be called there) (____) _____

Occupation: _____

Hobbies & Other Special Interests: _____

Languages Other Than English: Spanish Sign Language Other _____

Best Time to Call You: _____

Relationship to Person with Special Needs:

- | | | | | | |
|----------------------------------|-----------------------------------|--------------------------------------|---------------------------------|---------------------------------|--|
| <input type="checkbox"/> Mother | <input type="checkbox"/> Sister | <input type="checkbox"/> Grandmother | <input type="checkbox"/> Self | <input type="checkbox"/> Aunt | <input type="checkbox"/> Agency/Professional |
| <input type="checkbox"/> Father | <input type="checkbox"/> Brother | <input type="checkbox"/> Grandfather | <input type="checkbox"/> Spouse | <input type="checkbox"/> Uncle | <input type="checkbox"/> Other |
| <input type="checkbox"/> Natural | <input type="checkbox"/> Adoptive | <input type="checkbox"/> Foster | <input type="checkbox"/> Step | <input type="checkbox"/> Friend | |

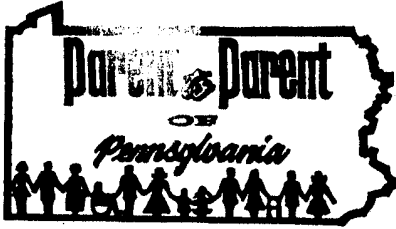
In what area(s) do you feel would be most helpful from other families? (Circle your top choice)

- | | | |
|---|--|---|
| <input type="checkbox"/> Activities of Daily Living | <input type="checkbox"/> <u>Inclusion</u> | <input type="checkbox"/> <u>Therapies</u> |
| <input type="checkbox"/> Adoption | <input type="checkbox"/> Community Inclusion | <input type="checkbox"/> Aqua Therapy |
| <input type="checkbox"/> Assistive Technology | <input type="checkbox"/> Religious Inclusion | <input type="checkbox"/> Auditory Integration Therapy |
| <input type="checkbox"/> Bereavement | <input type="checkbox"/> School Inclusion | <input type="checkbox"/> Autism (type) _____ |
| <input type="checkbox"/> Condition | <input type="checkbox"/> Independent Living | <input type="checkbox"/> Equestrian Therapy |
| <input type="checkbox"/> Developmental Toys | <input type="checkbox"/> MA (Medical Assistance) | <input type="checkbox"/> Music Therapy |
| <input type="checkbox"/> Early Intervention | <input type="checkbox"/> Medical Equipment | <input type="checkbox"/> Occupational Therapy |
| <input type="checkbox"/> Educational Needs | <input type="checkbox"/> Medical Expenses/Hospitalization | <input type="checkbox"/> Physical Therapy |
| <input type="checkbox"/> Elderly Parents | <input type="checkbox"/> NICU/PICU | <input type="checkbox"/> Speech Therapy |
| <input type="checkbox"/> Employment Issues | <input type="checkbox"/> Peer Socialization | <input type="checkbox"/> Vitamin/Nutritional Therapy |
| <input type="checkbox"/> Experienced with use of Specialized Equipment (Describe) _____ | <input type="checkbox"/> Private Placements | <input type="checkbox"/> Other _____ |
| | <input type="checkbox"/> Recreational Activities | _____ |
| <input type="checkbox"/> Feeding Issues | <input type="checkbox"/> Respite Care | _____ |
| <input type="checkbox"/> Financial Concerns | <input type="checkbox"/> Sibling Relationships | |
| <input type="checkbox"/> Foster Care | <input type="checkbox"/> Single Parenting | |
| <input type="checkbox"/> Grandparent Relationships | <input type="checkbox"/> SSI/SSDI (Social Security Income) | |
| <input type="checkbox"/> Home Schooling | <input type="checkbox"/> Stress | |
| <input type="checkbox"/> IEPs and IFSPs | <input type="checkbox"/> Support Groups | |

Are you a member of a support group? No Yes If yes, which ones? _____

How did you hear about the Parent to Parent Program?

- | | | | |
|---|-------------------------------------|---|---|
| <input type="checkbox"/> Agency/School | <input type="checkbox"/> CONNECT | <input type="checkbox"/> Presentation | <input type="checkbox"/> Other (Describe) |
| <input type="checkbox"/> Another Parent | <input type="checkbox"/> Newsletter | <input type="checkbox"/> Special Kids Network | _____ |
| <input type="checkbox"/> Called Before | <input type="checkbox"/> Brochure | <input type="checkbox"/> Television | _____ |



PARENT TO PARENT OF PENNSYLVANIA PERSON WITH SPECIAL NEEDS INFORMATION

Name: _____ Age: _____ Birth date: _____

Medical Diagnosis: _____

If disability was a result of an accident, please check type

- Automobile Farming Recreation
 Other _____

Condition(s):

- | | | |
|--|---|--|
| <input type="checkbox"/> Abuse and Neglect
<input type="checkbox"/> ADD
<input type="checkbox"/> Allergies (severe)
<u>Amputation</u>
<input type="checkbox"/> Upper Extremity
<input type="checkbox"/> Lower Extremity
<input type="checkbox"/> Arthritis
<input type="checkbox"/> Asperger's syndrome
<input type="checkbox"/> Asthma
<input type="checkbox"/> Attention Deficit (ADHD)
<input type="checkbox"/> Autism
<input type="checkbox"/> Behavior Disorder
<input type="checkbox"/> Cerebral Palsy
<input type="checkbox"/> Chronic Renal Failure
<input type="checkbox"/> Cleft Lip/Palate
<input type="checkbox"/> Congenital Heart Disease | <input type="checkbox"/> CNS Injury
<input type="checkbox"/> Cystic Fibrosis
<input type="checkbox"/> Developmental Delay
<input type="checkbox"/> Diabetes Mellitus
<input type="checkbox"/> Down Syndrome
<input type="checkbox"/> Eating Disorders
<input type="checkbox"/> Hand Control Impairment
<input type="checkbox"/> Head Injury/Brain Injury
<input type="checkbox"/> Hearing Impairment
<input type="checkbox"/> Hemophilia
<input type="checkbox"/> HIV Infection
<input type="checkbox"/> Hydrocephaly
<input type="checkbox"/> Learning Disability
<input type="checkbox"/> Leukemia
<input type="checkbox"/> Mental Retardation
<input type="checkbox"/> Microcephaly | <input type="checkbox"/> Mobility Impairment
<input type="checkbox"/> Multiple Sclerosis
<input type="checkbox"/> Muscular Dystrophy
<input type="checkbox"/> Neurofibromatosis
<input type="checkbox"/> Orthopedic Impairments
<input type="checkbox"/> Phenylketonuria
<input type="checkbox"/> Prematurity
<input type="checkbox"/> Seizure Disorder
<input type="checkbox"/> Speech Impairment/Delay
<input type="checkbox"/> Spina Bifida
<input type="checkbox"/> Sudden Infant Death Syndrome
<input type="checkbox"/> Visual Impairment
<input type="checkbox"/> Other (Describe)
_____ |
|--|---|--|

Level of Function:

- Cognitive Level** Normal Mild Delay Moderate Delay Severe Delay Unknown Other _____
Mobility Normal for Age Crawls Walks Uses Walker Uses Crutches Uses Wheelchair
 Uses Power Chair Other _____
Speech Normal for Age Difficult to Understand Nonverbal Uses Speaking Device
 Uses Sign Language Other _____
Hearing Normal Impaired Deaf Other _____
Vision Normal Impaired Wears Glasses Blind Other _____
Behavior Normal Overactive Underactive Aggressive Other _____
Toilet Skills Normal for Age In Diaper In Diaper Only at Night Catheterization Self-Catheterization
 Other _____
Diet/Eating Skills Normal for Age Some Help Needed Button Feeding Tube Line Feeding Tube Regular Diet
 No Help Needed Fed By Others NG Feeding Tube Special Diet Other _____
Special Equipment Colostomy Computer Shunt Tracheotomy Ventilator Monitor Hearing Aids
 Suction Communication Device (Describe) _____ Other _____

Medications _____

School District _____ School Name _____

Services received _____ Provider of Service _____

Location of Service _____

Number of Children in Family:

Total Number of Children in Family _____ Ages: _____
 Number of Children in Family with Special Health Care Needs: _____ Ages: _____

In Database

Communication Log:	Date:	Continuing:	Closed:
Matched By _____	_____	_____	_____
Referred to: _____	_____	_____	_____
Information Sent: _____	_____	_____	_____

(All sections need notes:)

Referred by: _____
Date: _____

Matched to: _____
Date: _____

Parent to Parent of Virginia Referred Parent Form

Parent Information:

(circle one)

Mom

Stepmom

Grandma

Foster Mom

Name: first _____ last _____

Address: _____ City _____ Zip _____

Telephone: () _____ (h) () _____ (w)

Education: _____ Occupation: _____

Language(s) spoken other than english: _____

(circle one)

Dad

Stepdad

Grandpa

Foster Dad

Name: first _____ last _____

Address: _____ City _____ Zip _____

Telephone: () _____ (h) () _____ (w)

Education: _____ Occupation: _____

Language(s) spoken other than english: _____

Marital status: Single Married Separated Divorced

Child with Disability:

Name: _____ Child lives at home? Yes No

Birthdate: _____ Sex: male female

Diagnosis/disability: (be specific) _____

When diagnosed? before birth at birth at the age of _____

Insurance: SSI/Medicaid Private None

The following is a check list that will help us make the best match possible. Please check all items that best describe your child's characteristics and experience, including past and present.

Degree of Impairment:

- Mild Severe
 Moderate Unknown

Mobility:

- Delayed
 Normal for Age
 Walks Independently
 Crawls, Scoots
 Wheelchair Self Operated
 Wheelchair with Assistance
 Walks with Supportive Devices

Speech:

- Delayed
 Clear & Understandable
 Difficult to Understand
 Not Understandable
 Nonverbal Communication
 Augmentative Communication
 Does Not Communicate
 Sign Language

Vision:

- Normal Vision
 Corrective Lenses
 Partial Loss
 No Vision

Hearing:

- Normal Hearing
 Hearing Aid
 Partial Loss
 No Hearing
 Cochlear Implant

Toilet Skills:

- Normal for Age
 Some Help Needed
 Not Trained
 Catheterization

Type of School/Program: (Circle)

- | | |
|--------------------|-------------------------|
| Not Attending | Regular Child Care |
| Special Child Care | Early Intervention |
| Regular Preschool | Special Ed Preschool |
| Regular Class | Self-Contained Class |
| Resource Room | Psychoeducational Class |
| Public School | Private School |
| Home School | |

HOSPITALIZATION/SURGERY

Surgery/procedure _____ Hospital _____

DOCTORS USED

<u>Name</u>	<u>Specialty</u>	<u>City</u>
_____	_____	_____
_____	_____	_____

EXPERTISE IN THE FOLLOWING

- Inclusion Adoption Insurance ADA Breast Feeding Genetics School Advocacy

PAST PRESENT

Diet/Eating Skills:

- | | | |
|------------------|--------------------------|--------------------------|
| Regular Diet | <input type="checkbox"/> | <input type="checkbox"/> |
| Special Diet | <input type="checkbox"/> | <input type="checkbox"/> |
| No Help Needed | <input type="checkbox"/> | <input type="checkbox"/> |
| Some Help Needed | <input type="checkbox"/> | <input type="checkbox"/> |
| Fed By Others | <input type="checkbox"/> | <input type="checkbox"/> |
| Feeding Tube | <input type="checkbox"/> | <input type="checkbox"/> |
| Gastrostomy Tube | <input type="checkbox"/> | <input type="checkbox"/> |
| Feeding Problems | <input type="checkbox"/> | <input type="checkbox"/> |

Behavior:

- | | | |
|-----------------|--------------------------|--------------------------|
| Typical for Age | <input type="checkbox"/> | <input type="checkbox"/> |
| Overactive | <input type="checkbox"/> | <input type="checkbox"/> |
| Underactive | <input type="checkbox"/> | <input type="checkbox"/> |
| Aggressive | <input type="checkbox"/> | <input type="checkbox"/> |

Treatments:

- | | | |
|----------------------|--------------------------|--------------------------|
| Physical Therapy | <input type="checkbox"/> | <input type="checkbox"/> |
| Occupational Therapy | <input type="checkbox"/> | <input type="checkbox"/> |
| Speech Therapy | <input type="checkbox"/> | <input type="checkbox"/> |
| Chemotherapy | <input type="checkbox"/> | <input type="checkbox"/> |
| Radiation Therapy | <input type="checkbox"/> | <input type="checkbox"/> |
| Lovass Therapy | <input type="checkbox"/> | <input type="checkbox"/> |
| Auditory Training | <input type="checkbox"/> | <input type="checkbox"/> |
| Patterning | <input type="checkbox"/> | <input type="checkbox"/> |
| Vision Therapy | <input type="checkbox"/> | <input type="checkbox"/> |
| ECMO | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (List): _____ | | |

Special Conditions/Equipment:

- | | | |
|---------------------|--------------------------|--------------------------|
| Apnea Monitor | <input type="checkbox"/> | <input type="checkbox"/> |
| Colostomy | <input type="checkbox"/> | <input type="checkbox"/> |
| Computer | <input type="checkbox"/> | <input type="checkbox"/> |
| Heart Monitor | <input type="checkbox"/> | <input type="checkbox"/> |
| IV | <input type="checkbox"/> | <input type="checkbox"/> |
| Oxygen | <input type="checkbox"/> | <input type="checkbox"/> |
| Shunt | <input type="checkbox"/> | <input type="checkbox"/> |
| Suction | <input type="checkbox"/> | <input type="checkbox"/> |
| Tracheostomy | <input type="checkbox"/> | <input type="checkbox"/> |
| Ventilator | <input type="checkbox"/> | <input type="checkbox"/> |
| Other (List): _____ | | |

Special Ed Classification: _____

Special Schools/Programs Attended (List): _____

Medication (List): _____



**New Jersey Statewide Parent to Parent
Phone Log For Supporting Parents**

Parent's name seeking support: _____

Address: _____

Home #: _____ Work#: _____

E-mail: _____

Name of child: _____ Age: _____

Siblings _____

Situation/Reason for Contact: (remember to share your experiences, be positive, but realistic, ask mom how she is doing; dad, siblings), LISTEN. *Space for notes!*

Information requested: (remember your resource guide)

Before you hang up, promise to call again. Below is space to record the date you called and comments about that call.

Date _____ *note* _____

Date _____ *note* _____

Date _____ *note* _____

Date _____ *note* _____

Remember to send a postcard to your Regional Parent Associate after each call!

APPENDIX I

Developing/Expanding a Statewide Parent to Parent Program – A Workbook

STATEWIDE PARENT TO PARENT
A Workbook/Planner

ORGANIZATIONAL ISSUES

- What are the advantages of a centralized statewide Parent to Parent program?
- What are the advantages of a de-centralized statewide Parent to Parent program?
- What existing organizational structures are already in place that a developing statewide Parent to Parent program could perhaps utilize?
- Where on the continuum of centralization/de-centralization should our statewide Parent to Parent program reside?
- What are the advantages of an autonomous statewide Parent to Parent program?
- What are the advantages of a sponsored statewide Parent to Parent program?
- Who could sponsor a statewide Parent to Parent program?
- Where on the continuum of autonomous/sponsored should our statewide Parent to Parent program reside?

FUNDING AND BUDGETS

- How much funding support will we need to launch a statewide Parent to Parent program?
- What are some possible public (local, state, federal) funding sources for launching a statewide Parent to Parent program?
- What process should we follow to request funds from these funding sources?
- What are some possible **private** (local, state, national) funding sources for launching a statewide Parent to Parent program?
- What process should we follow to request funds from these funding sources?
- What funding sources might be approached for long-term funding of a statewide Parent to Parent program?
- How and when should discussions with potential long-term funding sources begin?

TRAINING SUPPORTING PARENTS

- What should the content be of training for supporting parents? What format should the training for supporting parents?
- As we develop our training component for supporting parents, what existing resources are available to us (materials and people)?
- Who should train supporting parents, and what at level(s) should training be provided?
- What kind of follow-up training and/or supports should be provided to supporting parents once they are matched, and who should provide this support?
- Will our Parent to Parent program match parents who have not been trained as supporting parents, and if so, how will these parents be prepared for their matched experience?

MATCHING PARENTS – DOCUMENTATION AND FOLLOW-UP

- Who will be matched by a statewide Parent to Parent program? Will the program be for just parents or also for extended family members or other primary caregivers? Will the program match families who have a child with special needs and/or will it match parents who have adults with special needs? How about matches for children/adults who are at risk?
- At what level(s), local, regional, and/or state, will referrals be received?
- At what level(s), local, regional, and/or state, will matches be made?
- How will matches be documented and at what level? What are possibilities for using computer technology in the documentation of matches?
- How will follow-up support be provided to each match and who will provide it?

NEXT STEPS

- What needs to happen next?
- How will we do it?
- Who will do it?
- By when?
- How will we know we have finished and are ready for the next step?

PUBLIC RELATIONS AND COLLABORATIVE PARTNERSHIPS

- How shall we get the word out about our statewide Parent to Parent program – to parents and to potential referral sources? Are there existing promotional activities that we can utilize?

- At what level(s) should promotional efforts occur?

- What other statewide activities might be interested in a collaborative partnership with our statewide Parent to Parent program?

- What resources are available through other existing statewide activities that could help to support the development of a statewide Parent to Parent program?

- As we consider collaborative partners, we will need to answer the questions:
 - What's in it for the statewide Parent to Parent program?
 - What's in it for other collaborating agencies?
 - And most importantly, what's in it for families?