

PARENT TO PARENT USA

Strengthening Patient and Family Engagement through Parent to Parent Support

WWW.P2PUSA.ORG

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Parent to Parent

What is Parent to Parent?

Organizationally, Parent to Parent (PtoP) programs offer parent to parent support as a core resource for families with children who have special health care needs, disabilities or mental health concerns. Through a one-to-one “match,” experienced support parents provide emotional support to families and assist them in finding information and resources. Parent to Parent programs are committed to listening and learning from families and developing an array of services and supports in response to family identified needs.

The Parent to Parent network is a growing national resource for families. Statewide, regional and local community-based programs continue to emerge out of grassroots efforts; new statewide Parent to Parent programs are being developed to support the efforts of local programs; national needs are being addressed as they arise; and international interest in Parent to Parent is growing every year. The strength of Parent to Parent comes directly from the parents who dedicate themselves to its continuing success.

What is Parent to Parent Support?

Parent to Parent USA defines parent to parent support as the intentional connection between a trained volunteer Support Parent and a parent seeking information, resources, guidance, and support from an experienced parent. Parent to Parent programs facilitate parent “matches” and provide follow-up support to assure the matched relationship meets peer expectations. Because the quality of the matched experience depends on a number of different factors, Parent to Parent programs make parent matches with great care, and use quality standards based upon research.

What are Parent to Parent USA Endorsed Practices?

The practices endorsed and promoted by Parent to Parent USA are based on research and the knowledge of experienced PtoP Program Directors. View the following files in PDF format:

[PtoP USA Endorsed Program Practices — Summary](http://www.p2pusa.org/wp-content/uploads/2017/03/Summary.EndorsedPractices.2.07.17.pdf)

<http://www.p2pusa.org/wp-content/uploads/2017/03/Summary.EndorsedPractices.2.07.17.pdf>

[PtoP USA Endorsed Practices for Matching and Follow-up](http://www.p2pusa.org/wp-content/uploads/2016/01/Endorsed-Practices-for-Matching-and-Follow-up.pdf)

<http://www.p2pusa.org/wp-content/uploads/2016/01/Endorsed-Practices-for-Matching-and-Follow-up.pdf>

How are PtoP Matches Made and Supported?

Parents who are interested in being matched with a Support Parent often self-refer to a Parent to Parent program or they can request that someone else make the referral on their behalf. Referrals and matches are never made, however, without the expressed interest and permission of the parent seeking the support, and anonymous referrals are never accepted. Usually the person who handles referrals to the Parent to Parent program is a parent, and parents find it comforting to talk to another parent right away. The referral coordinator, in order to ensure the most successful match, will gather information from the referred parent about (a) the child; (b) diagnosis and specific challenges; (c) reasons for seeking support; (d) the qualities they hope for in a support parent; and (e) any unique preferences or issues related to the match. The referral coordinator will then check the roster of trained and available Support Parents to identify a Support Parent who seems to be the right fit. If the support parent agrees to the match, then contact information for each parent is shared with the other and the match is made. After the match is made, follow-up activities help to ensure the success of the match. An initial call to both parents lets the coordinator know the match has been made and to know if additional support or resources are needed.

What are the characteristics of Parent to Parent?

Most Parent to Parent programs are parent-directed, and indeed it is this parent ownership and energy that seem to give the program their real strength.

Most Parent to Parent programs are all inclusive and serve families of children/adults of all ages.

Most Parent to Parent programs represent cross-disabilities, individuals with special health care needs and mental health concerns, severe behavioral and emotional challenges, and/or children with acquired disabilities or who are born prematurely. Each match evolves based upon the needs and preferences of the referred parents — some matches are just a few contacts over a course of several days or weeks; while others

evolve into lifelong friendships.

100% of PtoP USA Alliance Members offer formal training for Support Parents.

What is the history of Parent to Parent?

The first formally organized Parent to Parent program, the Pilot Parents Program, was started in Omaha, Nebraska by a young mother of a child with Down syndrome. She worked closely with a social worker at the Greater Omaha Arc who shared her vision of a program to foster 1-1 connections between parents. The program grew rapidly and within a few years the founders received a federal grant to train others to replicate the Pilot Parent model. Parent to Parent programs began to spring up nationwide, fueled by the energies and commitments of parents who believed fervently in their importance. See history of the Parent to Parent Movement and the history of Parent to Parent – USA.

How is Parent to Parent Part of a Comprehensive System of Family Support?

There are many different parent support and information opportunities available to parents – some are directed by professionals and others are directed by parents; sometimes the support is provided in a group setting and sometimes the support is provided individually. Ideally, communities will offer parents a broad spectrum of parent support options so that parents can choose the one that is most comfortable and meaningful for them. Sometimes parents want to talk individually with a professional about a particular issue or need. Support that is provided by professionals in a one-to-one setting can be either informational or emotional support. The one-to-one nature of this support means that it can be easily tailored to the specific needs or concerns of the parent.

When parents are given a choice as to whom they would want to speak with about their child, they most often mention as a first-choice other parents who are sharing their experiences. Sharing family experiences with others in similar circumstances is an important source of social support. Literally hundreds, if not thousands, of parent support groups have been started by parents wishing to talk with other parents about similar issues. Parent to Parent support rounds out this continuum of support – providing parents with one-to-one emotional and informational support from another parent who has been there.

Parent to Parent (PtoP) programs are a free and confidential service designed to connect parents and caregivers of individuals with disabilities or special health care needs with trained volunteer support parents who have experience raising children with disabilities. Parenting a child with autism, cerebral palsy, intellectual disabilities, physical disabilities, complex medical needs, or genetic and other disorders can be an overwhelming and potentially isolating experience. Parents work to become experts in

their child's disability, learn a new vocabulary of medical and therapeutic terms, and navigate a labyrinth of services, therapies, insurance issues, and public systems to access to the best treatments and school settings possible.

When parents receive a disability diagnosis or enter into a stressful transition period, the support of another parent who has encountered similar experiences can be an important avenue to help families regain their sense of strength and independence. PtoP helps families share information and experiences, and create relationships that can be long-lasting and mutually beneficial.

The focal point of the program is the matching system through which families looking for support are matched with experienced families who have "been there." PtoP maintains a database of volunteer support parents who have received training to provide empathetic listening, coping strategies, and resource information to parents needing help. Contact may be made by phone, face-to-face, or via email.

New families are either referred to the program by a professional or are self-referred through word of mouth and/or program outreach efforts. When a new family contacts the program, they are asked to complete a short intake form which provides contact information, a brief description of their child's disability, and what the parent is looking for in a support parent. The information provided in these forms is then used in the matching process. While matches are most frequently made based on the child's disability, they can also be made using other criteria, such as experience with particular therapies, IEP expertise, a common native language, or geographical location. PtoP is continually recruiting support parents, so that newly referred parents can be matched as quickly as possible, and to cover a wide range of needs and disabilities.

Several times per year, PtoP programs may host informal family get-togethers to enable program participants and families to meet one another in a fun and relaxed setting. They may also host periodic informational sessions on a wide range of topics of interest to parents of children with disabilities.

Identifying emotions experienced

Emotional States	What does it look or feel like?	Common Behavior	What to do?
Shock	<ul style="list-style-type: none"> · Numb/Quiet · Detached or Removed · Hysteria 	<ul style="list-style-type: none"> · Withdrawn · Silent with very little response · Hysterical, out of control · Avoiding subject 	<ul style="list-style-type: none"> · Accept each person's reactions as normal for them. Avoid trying to make others act your way. Be with someone (When you are ready.)
Panic	<ul style="list-style-type: none"> · Very Anxious · Helpless · Wish to run away · Overwhelmed 	<ul style="list-style-type: none"> · Cannot plan things · Disorganized · Forgets things · Tense 	<ul style="list-style-type: none"> · Let your feelings happen, don't hold them in. Allow others to take over some daily activities for you. Talk to someone.
Denial & Disbelief	<ul style="list-style-type: none"> · Overwhelmed · Full of Doubt · Helpless · Anxious 	<ul style="list-style-type: none"> · Search for other opinions · Resist change of plans · Refuse to talk about it · Deny having a child <i>"like that"</i> · Sleep more, without feeling rested · Talk about <i>"aches and pains"</i> · Keep very busy, avoid 	<ul style="list-style-type: none"> · Allow self to delay acceptance until ready. Allow self to delay talking about it until ready. · Get extra rest, eat well. · Turn over chores to someone else. · Do not feel bad for getting other opinions. · It is alright to talk about your aches and pains. · Begin to find out facts
Anger & Fear	<ul style="list-style-type: none"> · Angry at everyone · Frustrated · Fear power of own anger · Bitter 	<ul style="list-style-type: none"> · Abrupt, cold · Interrupt people · Blame others · Say <i>"why me?"</i> · Keep distance from child · Lash out at others · Frightened by lack of control 	<ul style="list-style-type: none"> · Do not put yourself down for feeling angry. Try to limit anger attacks. Explain that you are angry at the whole situation. · Apologize if you unintentionally hurt someone. · Realize that others feel helpless. · Do not be surprised if you keep getting angry.

Emotional State	What does it look or feel like?	Common Behavior	What to do?
Sadness & Despair	<ul style="list-style-type: none"> · Guilt · Shame · Emptiness · Sadness 	<ul style="list-style-type: none"> · Blame yourself · Put yourself down · Depressed, slow to react · Crying, loss of appetite, inability to sleep, irritable · May have strong sexual desires or no sexual desires · Keep distance from friends with children · Investigate committing child to an institution 	<ul style="list-style-type: none"> · Realize that no one is to blame. · Expect to feel depressed and tired. · Seek someone to talk with about feelings. · Ask help in making daily plans. · Rest and eat well. · Try to spend more time with your child
Hope	<ul style="list-style-type: none"> · Wish for help · Feelings less intense · Waves of depression continue · Fear of the future and ability to handle it 	<ul style="list-style-type: none"> · Search for reason or cause · Struggle to look for normal aspects of child · See parts of self in child · Express that the sad feelings continue to come back 	<ul style="list-style-type: none"> · Spend more time with your child. · Be realistic, let go of false hope. · Get facts and connect to other parents with similar experiences. · Get help from everyone who wants to help. · Expect waves of depression with less frequency and intensity.
Adoption	<ul style="list-style-type: none"> · Begin to feel more satisfaction with life · Feel closer to your child 	<ul style="list-style-type: none"> · Search for acceptance from others for self and child · Seek help from others to correct child's problem or adapt to it 	<ul style="list-style-type: none"> · Actively participate in your child's treatment. · Focus on your child's strengths · Offer help to others who may be experiencing some of these reactions.