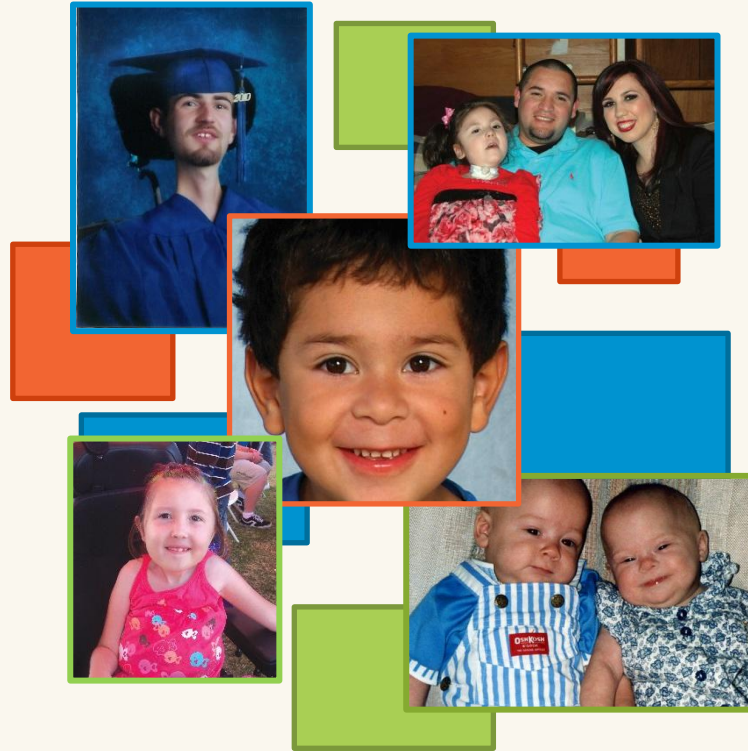




Raising Special Kids

Families Helping Families



Strengthening Families to Improve
Outcomes for Children with Disabilities

Salasek Family



Routine Ultrasound at 22 weeks



Mission

To improve the lives of children with the full range of disabilities and special health conditions by helping parents become effective advocates



Programs and Services



Accurate, authoritative information related to your child's disability or special health condition.



Connections with a trained Parent Mentor skilled at providing information and support.



Special education consultations, training, and problem-resolution services.

Systems of Care



Parent to Parent Support

Parent to parent support is the heart of our mission.

The goal of Parent to Parent support is to provide direct support and information to families.



Why Peer Support?

For 35 years, Raising Special Kids has seen and documented the benefit of parent training and education provided through a model of Peer Support, from parents of children with disabilities. This Peer to Peer support model, sometimes referred to as Parent to Parent support, is an evidence-based practice with outcomes that are supported with data.

Research findings show parents of children with disabilities highly value Peer to Peer knowledge and support, that it could not come from any other source, and that it is one of their most effective sources of knowledge and information.

(Singer GHS, Marquis J, Powers LK, et al., J Early Intervention, 1999; Ainbinder JG, Blanchard LW, Singer GH, et al., J Pediatric Psychology, 1998)



The Diagnosis

Balancing Realism with Hope



The communication of an initial diagnosis impacts the family's ability to:

- Accept and support their child,
- Access needed supports and resources, and
- Attain successful outcomes for their child



Common Family Responses to a Diagnosis

- Denial
- Fear
- Confusion
- Rejection
- Anger
- Guilt
- Powerlessness
- Disappointment
- Acceptance
- Hope

Parents may accept the diagnosis in different ways



Assessing Parent 'Readiness'

- Have I accepted my family's situation?
- Do I have enough time to give comfortably to others in need?
- How comfortable am I in reaching out and providing support to families?
- How comfortable am I in listening to other people's problems?
- How comfortable am I in relating to people who may have values or feelings different from my own?
- Am I willing to be open and honest about my experience with families seeking support?
- Can I refrain from talking to others about the families I have contacted?



Parent Leader Training Elements



- Good listening skills
- People First Language
- Describe, Don't Prescribe
- Portion and Moderation
- Keeping track – updating information about important family changes
- Evaluations
- Confidentiality
- Ethical Guidelines



Parent to Parent Mentoring

Individual mentoring and coaching for 8 weeks

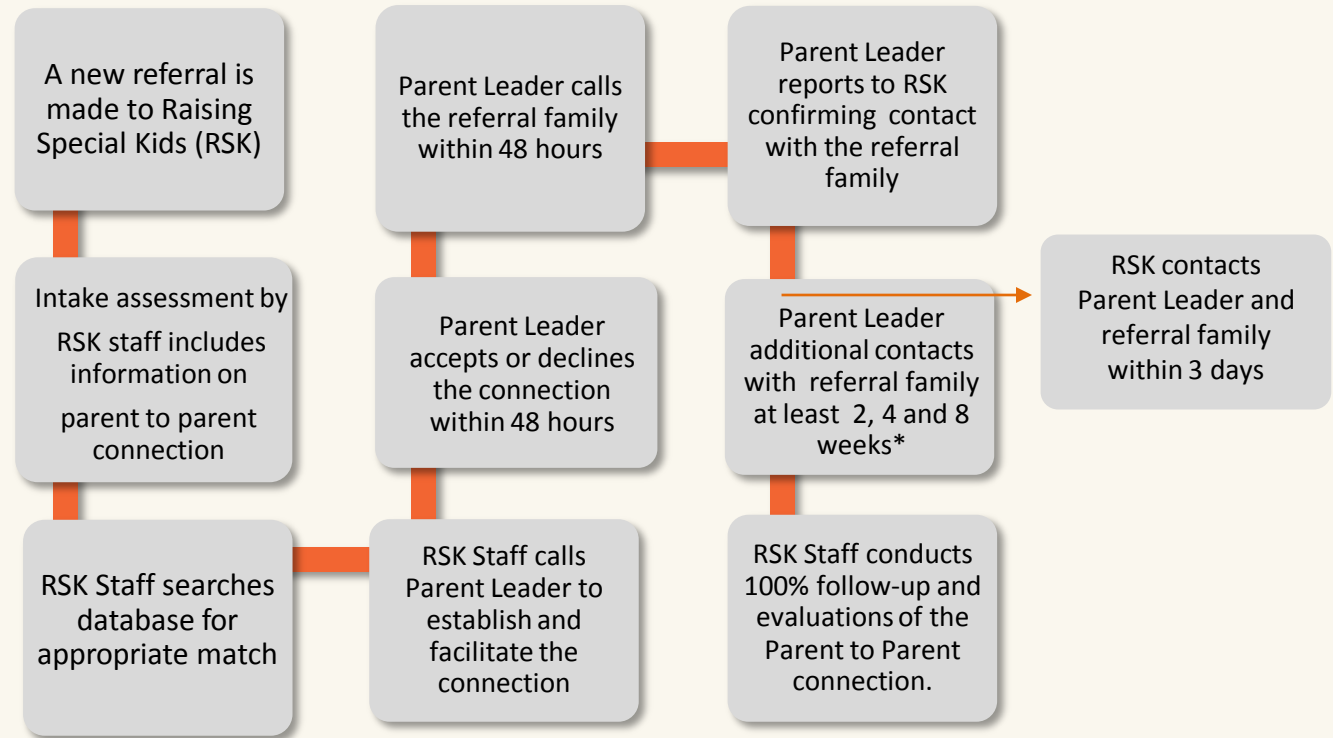
- Confidential
- Open eligibility
- Offered at no charge
- Available in Spanish
- Monitored and evaluated at 2, 4, and 8 weeks

Referrals: DDD Support Coordinators, AzEIP, NICU Staff, Social Workers, Physicians, Schools, Clinics, Community programs



P2P Process

How Does it Work?



- Raising Special Kids Staff monitors and supervises Parent Leaders to ensure continuing contact with the family and quality of support.
- P2P protocol meets best practice standards of the national technical assistance center (P2P USA)

P2P Match Criteria

Child's Diagnosis

Age and Gender of Child

Presenting Issues

Culture/Language/Ethnicity of Parent

Geographical Area

*"I am looking for a parent match with a family whose infant has the diagnosis of **Proximal Focal Femoral Deficiency, Class A**. The parents are weighing the options of amputation versus lengthening and the family needs to speak with parents who have made a similar decision, especially within the last 5 years given new technology and advancements in treatment."*



P2P Outcomes

2015 Evaluation Data Likert Scale 1-5 **4.5 or > in each area**

- Improves a parent's knowledge and skills in making informed health care decisions and advocating for appropriate services
- Help parents better understand and manage their child's needs, services, and care
- Increases effective collaboration with professionals
- Provides emotional support for the challenges of parenting a child with a disability or special health condition.

98% Would recommend P2P support to another parent

N= 379



It Takes Family Support

- For parents to gain useful and practical knowledge to make informed decisions, better understand their child's needs and services, and navigate within systems of care.
- To facilitate collaboration between parents and professionals and improve outcomes for children
- For parents to have the emotional support to move from isolation and grief into a network of families experienced in self-advocacy
- To ensure the family voice is represented at a systems level



P2P USA



<http://www.p2pusa.org/parents/>



Parent Training and Information Center (PTI)

<http://www.parentcenterhub.org/find-your-center/>

Every State has at least one **Parent Training and Information Center (PTI)** to offer families support & information. Many States also have a **Community Parent Resource Center (CPRC)**, which offers the same type of support and training to parents of children with disabilities.



How to Refer a Family to Raising Special Kids

Families can always contact us directly

602-242-4366 or 800-237-3007

info@raisingspecialkids.org

Or complete our referral form so we can contact the family. Forms are available at

www.raisingspecialkids.org

We will follow up with you after making contact with the family you referred!

Thank you!
Nannette Salasek

nannettes@raisingspecialkids.org

For support & information please call
us at: **602-242-4366**