Strengthening Families to Improve Outcomes for Children with Disabilities
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.**
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.

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
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?

A new referral is made to Raising Special Kids (RSK)

Intake assessment by RSK staff includes information on parent to parent connection

RSK Staff searches database for appropriate match

Parent Leader calls the referral family within 48 hours

Parent Leader accepts or declines the connection within 48 hours

RSK Staff calls Parent Leader to establish and facilitate the connection

Parent Leader reports to RSK confirming contact with the referral family

Parent Leader additional contacts with referral family at least 2, 4 and 8 weeks*

RSK Staff conducts 100% follow-up and evaluations of the Parent to Parent connection.

RSK contacts Parent Leader and referral family within 3 days

• 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)

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.

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