

# Enhancing Person and Family Engagement with Parent-to-Parent Peer Support

Webinar

September 25, 2018



INSTITUTE FOR PATIENT- AND  
FAMILY-CENTERED CARE

**Patient-Centered**  
**Primary Care**  
COLLABORATIVE



# Today's Speakers



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Senior Policy and  
Program Specialist



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Director



## Objectives

- Understand the importance of parent-to-parent mentoring support to achievement of improved outcomes and satisfaction
- Invite TCPI clinic participation in linking families with a parent-to-parent mentor





- Setting the Stage: Person and Family Engagement in TCPi and How Peer Support Can Help
- Raising Special Kids Program Overview
- Review of Parent-to-Parent Support Opportunity for TCPI Practices
- Q & A

How We'll Spend Our Time



# About – PCPCC

## Patient Centered Primary Care Collaborative (PCPCC)

Mission: To promote collaborative approaches to primary care improvement



Patient-Centered Care

Person Family Engagement

Patient Activation

Improved Cost/Quality/Experience Outcomes

**PCPCC Support and Alignment Network** is a collaborative approach to improving person and family, clinician, and community strategies for engagement



# The PCPCC SAN: What We Do

We promote deeper patient relationships and community engagement among care teams through technical assistance and other resources.

## We offer the TCPI Community of Practice:

- Virtual and in-person learning events
  - Scholarships to conferences and training events
  - Coaching sessions for patient advisors and practices
  - *Choosing Wisely* resources
- Expert faculty in the field of patient advocacy and community health to PTNs
  - Online tools and resources
  - PFCC.Connect: A virtual community for patient partners

Visit PCPCC for tools and Resources: <http://www.pcpcc.org/tcpi>



# PCPCC SAN Message



## **Person and family engagement is a core element of effective and efficient clinical care.**

When people and their families are engaged to become partners in health, it drives better outcomes, reduces costs, and improves clinician satisfaction.



**Value of the SAN: We support PTNs and clinicians to develop person, family, and community engagement capability** as a transformative activity and as a tactic to meet cost and quality goals.



**Opportunity: PTNs can use SAN assets to accelerate initiatives targeting cost and quality improvement. It's not "another thing to do."**

TCPI PFE Metrics are integrated into PTN transformation strategies to improve adoption among targeted practices.

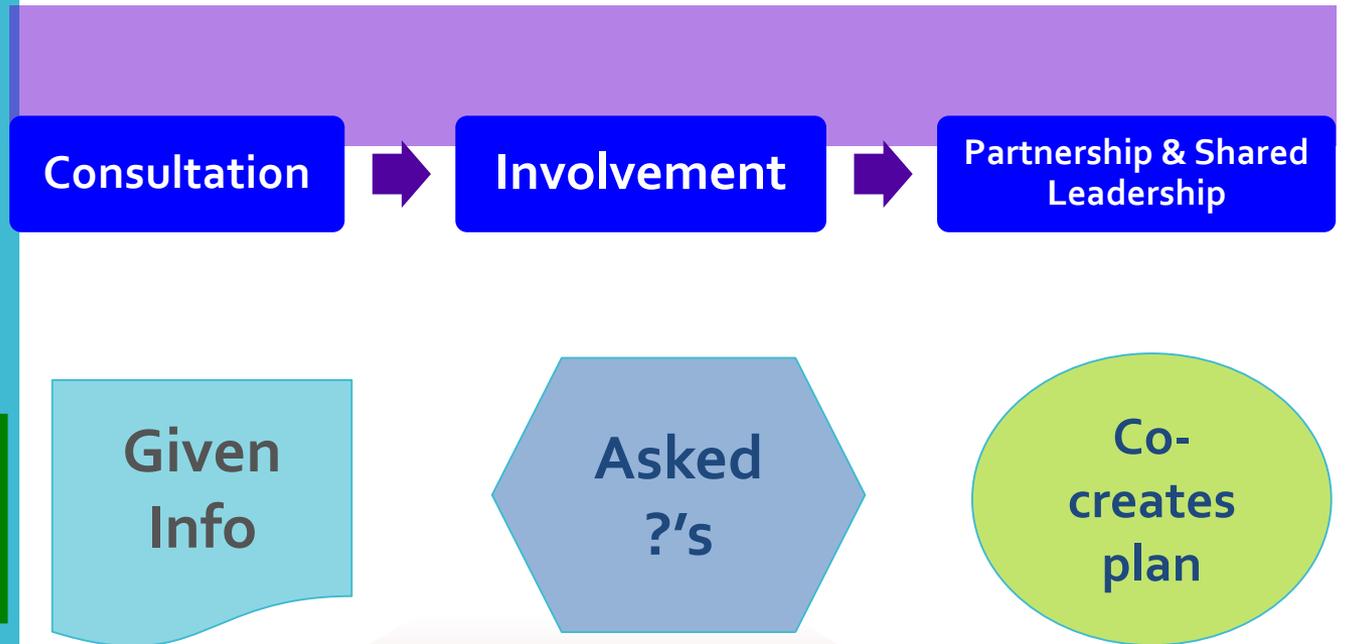


# Shared Goals: Meet the TCPI Aims

- 1 Support more than 140,000 clinicians in their practice transformation work
- 2 Improve health outcomes for millions of Medicare, Medicaid and CHIP beneficiaries and other patients
- 3 Reduce unnecessary hospitalizations for 5 million patients
- 4 Generate \$1 to \$4 billion in savings to the federal government and commercial payers
- 5 Sustain efficient care delivery by reducing unnecessary testing and procedures
- 6 Transition 75% of practices completing the program to participate in Alternative Payment Models
- 7 Build the evidence base on practice transformation so that effective solutions can be scaled



# Continuum of Patient Engagement



Direct  
Care

## Factors influencing engagement:

- Patient (beliefs about their role, health literacy, education)
- Organization (policies and practices, culture)
- Society (social norms, regulations, policy)



Person and  
Family  
Engagement  
Performance  
Metrics

## Governance

- Support for Patient and Family Voices

## Point of Care

- **Shared Decision Making**
- E-tool Use

## Policy and Procedure

- **Patient Activation**
- **Health Literacy Survey**
- **Medication Management**



# Peer Support Enhances Your Person and Family Engagement

- Increase **patient/family activation** by building connections with others who demonstrate confidence, skills and knowledge in managing their chronic conditions
- Improve **health literacy** by linking individuals with those who have a lived experience with navigating the health care system
- Enhance **shared decision-making** and **medication management support**



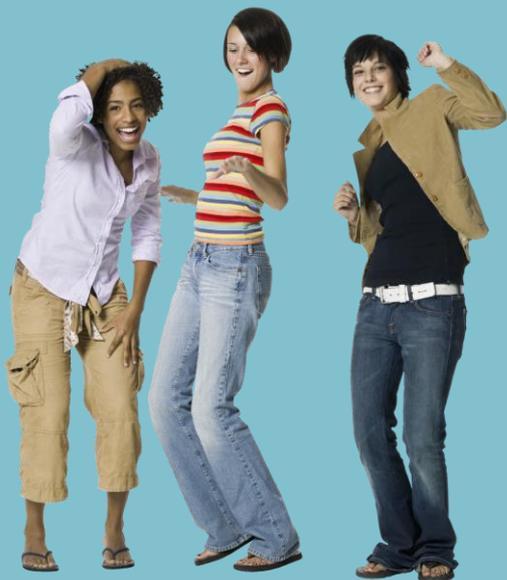
## Enhancing Care in Practices and Clinics

- Saves time (peers answer questions and provide support so patients seek less from provider)
- Provides valuable info on living with condition and practical tips providers don't know-teaches self management
- Increases adherence to treatment plans\*
- Improved patient outcomes\*
- Increased patient and family access to community resources



*"To know the road ahead, ask those on the way back"*

*Chinese Proverb*



Delivered by those with **common life experience**, peer support recognizes the unique capacity to help each other based on shared affiliation and deep understanding of experience.

Substance Abuse and Mental Health Services Administration

“...it’s a connection with **someone else who’s been there** and who might be able to help provide some guidance on what works well for them, who’s just a listening ear and, you know, a kind heart who’s willing to step up and be there for you if needed.” Peer mentor, Dee’s Place

# What is Peer Support?



# What are the Benefits to the Patient or Family Member?

Practical, Experiential Knowledge

Connections to others who have survived and even thrived

Deeper understanding and insight into one's health challenges and the decisions at hand

New skills and behavioral changes

Benefits specific to mentors



# Quality and Safety Controls : Role Clarity

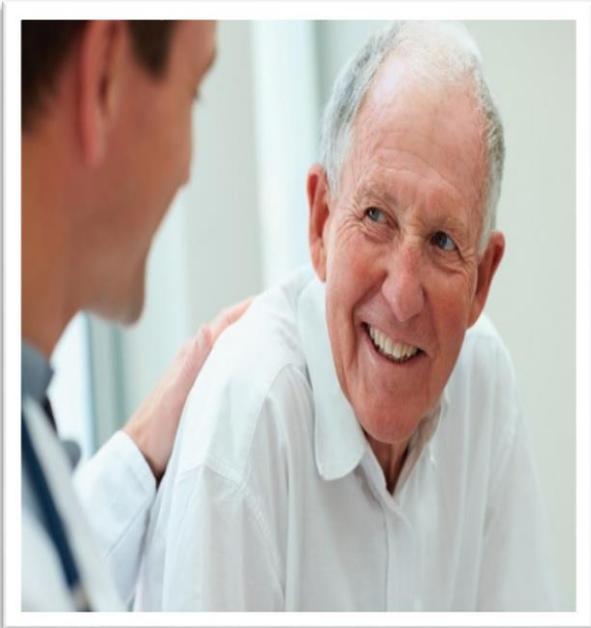
- Knowledge from personal experience
- Emotional support via shared experience

Peer  
Supporter

Knowledge from education and training

Support via counseling, problem-solving, skill development training

Professional



Understand the function and value of  
peer support

Be ready to have the conversation

Know the appropriate resources

Make no assumptions

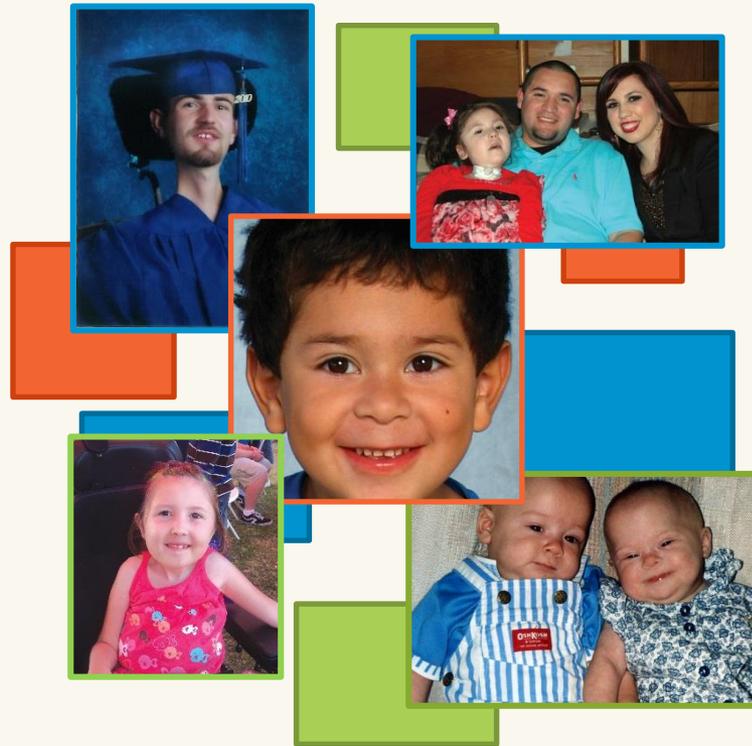
## Integrating Peer Support into Practices





# Raising Special Kids

Families Helping Families



Strengthening Families to Improve  
Outcomes for Children with  
Disabilities

# Mission

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



# Statewide Programs and Services



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



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



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



Education and coaching for parents to learn the most effective methods in managing challenging behavior.

# Why Parent-to-Parent Peer Support?

For **39 years** Raising Special Kids has:

- Connected parents to a model of Peer Support
- Documented the benefits of parent training and education
- Established 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)*



# Preparing Parent Mentors

- 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 Mentor 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 Match Criteria

***Child's Diagnosis***

***Age and Gender of Child***

***Presenting Issues***

***Culture/Language/Ethnicity of Parent***

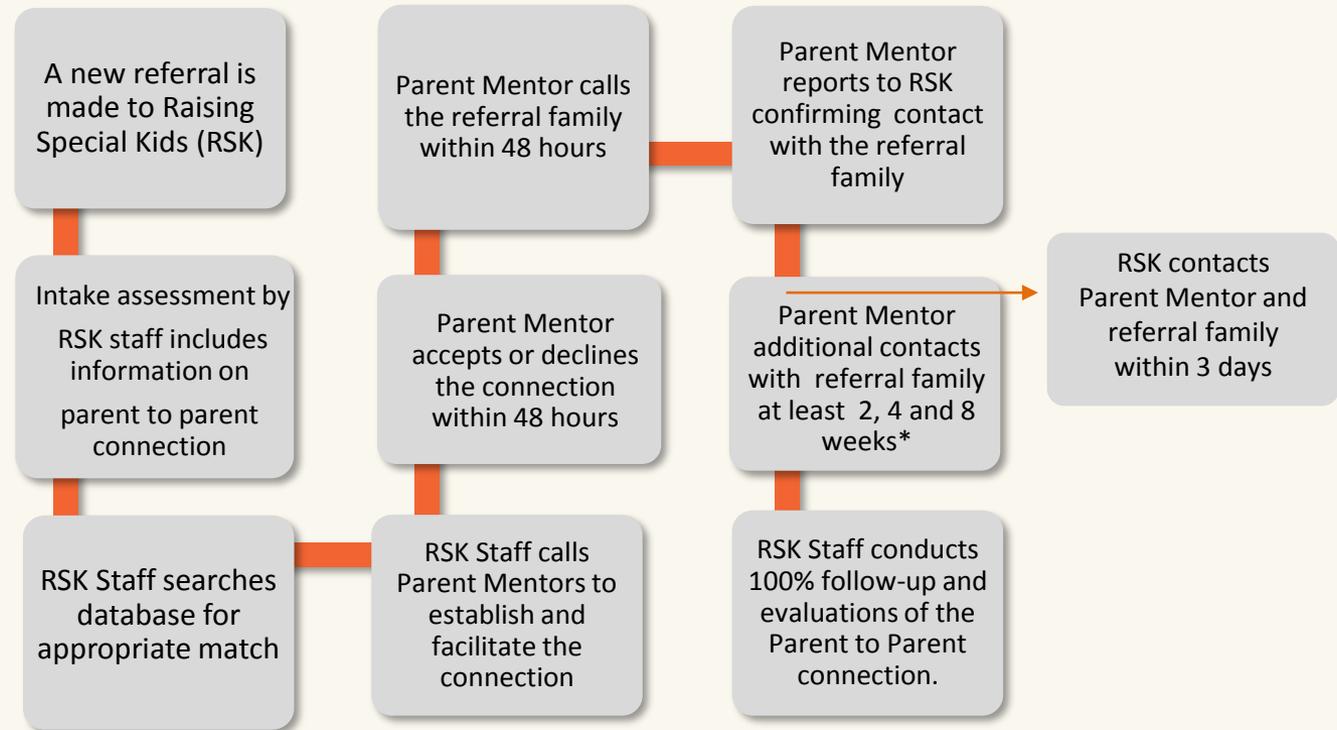
***Geographical Area***

\*\*Can be a very specific request for a match or diagnosis; while also can be as common as family with a child with speech delay.



# P2P Process

## How Does it Work?



- Raising Special Kids Staff monitors and supervises Parent Mentors 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 Outcomes

2017 Evaluation Data **4.5 or > in each area**

(Likert Scale 1-5-Highest)

- 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.

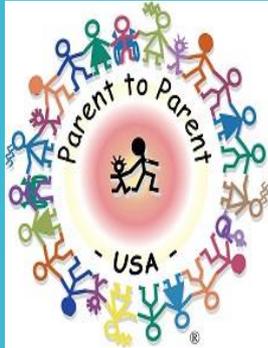
**98% Would recommend P2P support to another parent**

N= 366





# Practice Participation: Next Steps



Arizona

Connecticut

Indiana

Wisconsin

- Engage and support your families
- Connect to parent-to-parent peer support resources
- Become a pilot practice and receive implementation support



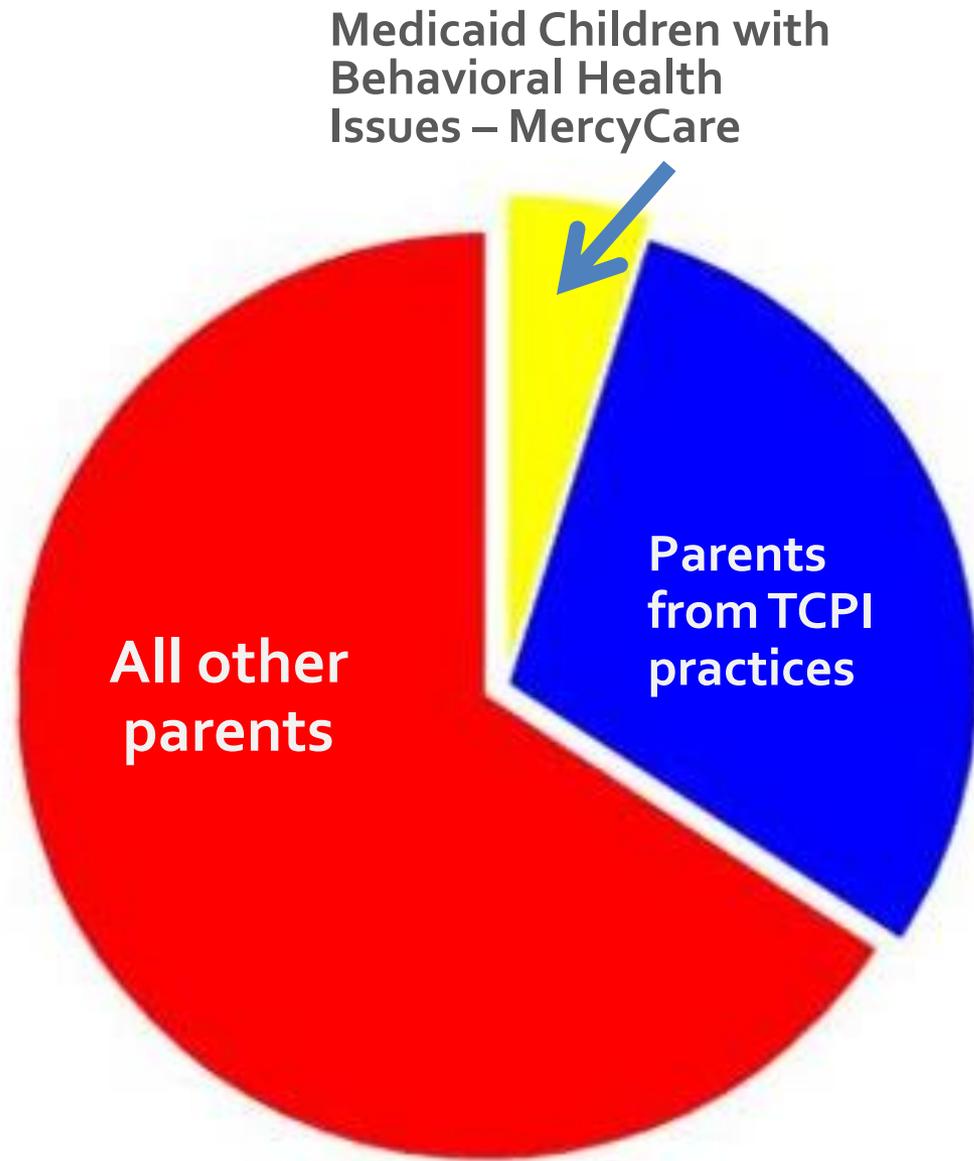
Parent  Parent of Wisconsin

...making connections statewide



# Raising Special Kids

## Who's Eligible?



# An Arizona Statewide Resource for All Parents

## Parents from TCPI Practices

- Clinic is Part of TCPI
- Insurance provider is not an issue
- Agree to participate
- Practice help evaluate the process

## All other Parents

- Live in Arizona
- Child has special needs

## Medicaid Children with Behavioral Health Issues

- Families covered by MercyCare
- Referred parent's child has a behavioral health issue
- Parent Mentor has a child in behavioral health system
- Parent Mentor has received training and been credentialed as a peer mentor

“No  
Wrong  
Door”



[www.raisingpecialkids.org](http://www.raisingpecialkids.org)

# Practice Role

- Practice agrees to participate and identifies a key contact
- Practice completes a referral form with each parent identified
- Practice faxes the referral form to Raising Special Kids (Spanish & English versions)
- Practice provides feedback on experience via phone survey at 3 mos.



## Family Referral Form

Fax: 602-242-4306

Email: [info@raisingspecialkids.org](mailto:info@raisingspecialkids.org)

Phone: 602-242-4366

Programs and services designed to help families **understand** their health care plan services, **find** community programs & resources, **connect** with other families and **participate** in developing an appropriate education for their children. All offered at no charge and without qualifying eligibility requirements.

### Professional Making Referral

Name (Print):



### Formulario de Referencia Familiar

Enviar al número de fax: 602-242-4306

Correo Electrónico: [info@raisingspecialkids.org](mailto:info@raisingspecialkids.org)

Phone: 602-242-4366

Programas y servicios diseñados para ayudar a las familias a **entender** los servicios de atención médica, a **encontrar** programas y recursos comunitarios, a **conectarse** con otras familias y a **participar** en el desarrollo de una educación apropiada para sus hijos. Todos nuestros servicios gratuitos y sin requisitos de elegibilidad.

#### Información del profesional que refiere

Nombre: \_\_\_\_\_ Fecha: \_\_\_\_\_  
Agencia/Organización: \_\_\_\_\_  
Número de teléfono: \_\_\_\_\_  
Correo electrónico: \_\_\_\_\_  
Firma: \_\_\_\_\_

#### Información de la familia

Al proveer la siguiente información y mi firma, autorizo a Raising Special Kids a iniciar contacto conmigo. Entiendo que al recibir esta remisión, Raising Special Kids me contactará en un lapso de 48 horas o de inmediato en casos urgentes. Toda información se trata con confidencialidad y no será compartida con individuos u organizaciones externas. Esta autorización es válida por un período de 30 días a partir de la fecha en que la heya firmado.

Nombre: \_\_\_\_\_  
Número de teléfono: \_\_\_\_\_  
Dirección: \_\_\_\_\_ Ciudad / Código Postal \_\_\_\_\_  
Correo electrónico: \_\_\_\_\_  
Nombre del niño: \_\_\_\_\_ Fecha de nacimiento: \_\_\_\_\_  
Diagnóstico del niño/necesidades especiales: \_\_\_\_\_

#### Permiso de la familia para compartir información

Por medio de la presente autorizo a que se entregue mi información familiar a Raising Special Kids. Entiendo que puedo esperar una llamada telefónica dentro de unos días después de ésta remisión.

Firma del padre o tutor: \_\_\_\_\_ Fecha: \_\_\_\_\_



# Other Partner's Roles

- **PTI:**
  - Share information about P2P program and referrals forms with TCPI practices
  - Assist practices in reporting their PFE strategy on the Practice Assessment Tool or reporting on adoption of PFE Metrics
  - Helps identify which referrals sites are TCPI
- **Raising Special Kids** processes all referrals:
  - Matches parents to Parent Mentor
  - Notifies practice of status of referrals
  - Works with practice on any issues or information needed to support referrals to program
  - Conducts satisfaction survey of parents referred
- **Institute for Patient- and Family-Centered Care**
  - Conducts phone interviews with practice on their experience

## Evaluations:

What can we learn to share?

- **Overall Program:**
  - Number of practices participating
  - Number of families referred and matched
  - Time from referral to match and from first parent mentor contact
- **Parents:**
  - Parent's experience with a parent mentor
- **Practices:**
  - Ease of referral
  - Timeliness of Referral feedback
  - Feedback from families about their experience

Questions?



# Webinars, Tools, Resources to Strengthen Your PFE Efforts!



The screenshot shows the website's header with the logo and navigation menu. The main content area features a purple banner with the text "Improving Care Through Partnership with Patients, Families & Communities". Below this, there is a paragraph about the PCPCC's Support & Alignment Network (SAN) and a link to "Learn More". At the bottom, there are three columns with icons and labels: "Patients & Caregivers", "Clinicians & The Care Team", and "Administrators & The Qi Team".

Patient-Centered  
Primary Care  
COLLABORATIVE

About Us ▾ The Medical Home ▾ Priority Issues ▾ Membership ▾ Resources ▾ Events ▾ News ▾

## Improving Care Through Partnership with Patients, Families & Communities

The PCPCC's **Support & Alignment Network (SAN)** provides technical assistance to practice improvement teams to foster partnerships with patients, family caregivers, and community-based organizations to achieve common goals of improved care, better health, and reduced costs.

Our work is supported by the Centers for Medicare and Medicaid Services (CMS), through the [Transforming Clinical Practice Initiative \(TCPI\)](#). This four-year initiative (2015-2019) is designed to assist more than 140,000 clinicians achieve large-scale health transformation. [Learn More](#)

 Patients & Caregivers

 Clinicians & The Care Team

 Administrators & The Qi Team

<https://www.pcpcc.org/tcpi>



- Institute for Patient- and Family-Centered Care

<http://www.ipfcc.org/bestpractices/peer-support.html>

- Peers for Progress (primary care resources) <http://peersforprogress.org/tools-training/primary-care/>

Websites: Selected Resources for  
General Peer Support



A free on-line learning community dedicated to partnerships with patients and families to improve and transform care across all settings.



INSTITUTE FOR PATIENT- AND  
FAMILY-CENTERED CARE

*PFCC.Connect*



## Join the Discussion

Ask or answer questions with your peers.

Our dynamic discussion groups explore best practices in patient- and family-centered care.

ANNOUNCEMENTS [ADD](#)

NEW FEATURES ON PFCC.CONNECT

BY: [MARY MINNITI](#), 16 DAYS AGO

Go to your profile and complete it! Then look under Network and see how many people that have similar roles or backgrounds as you! [More](#)



<http://pfcc.connect.ipfcc.org/home>

Thank  
You!

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