

# Strengthening Patient and Family Engagement Through Parent to Parent Support

Webinar

September 21, 2018



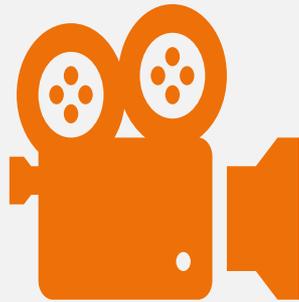
INSTITUTE FOR PATIENT- AND  
FAMILY-CENTERED CARE

Patient-Centered  
**Primary Care**  
COLLABORATIVE



Member of the Parent to Parent USA Alliance,  
Committed to Parent to Parent USA-Endorsed Practices

# Before We Begin



**We will send  
you  
the recording**



**Participate in  
the  
conversation!**

**Add your  
comments to  
the chat box**



**Submit your  
questions  
anytime**

**We'll do Q&A  
at the end of  
the  
presentation!**



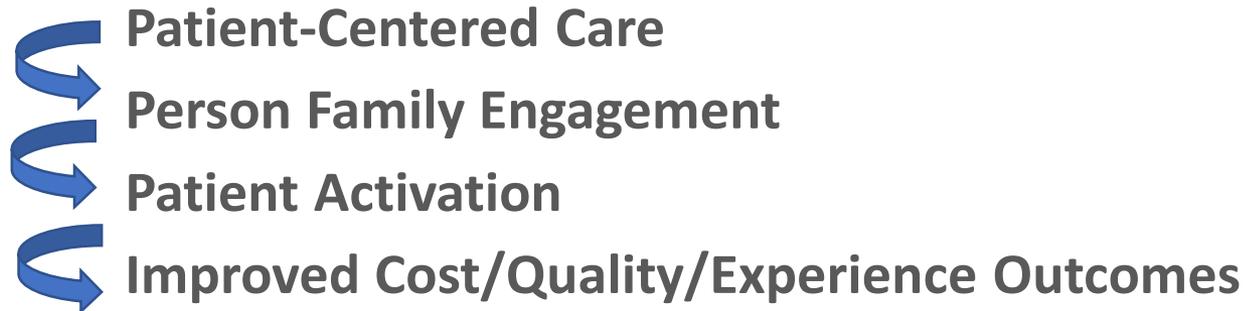
**Please  
complete the  
post-webinar  
survey**



# About – PCPCC

## Patient Centered Primary Care Collaborative (PCPCC)

Mission: To promote collaborative approaches to primary care improvement



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



# 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.



# Our Goal: 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



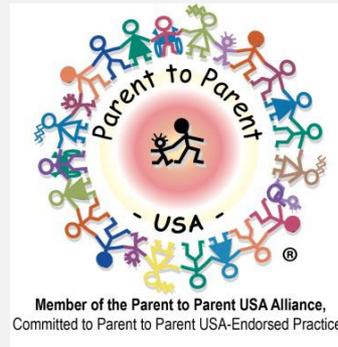
# Today's Speakers



INSTITUTE FOR PATIENT- AND  
FAMILY-CENTERED CARE



**Mary Minniti,**  
**CPHQ**  
Senior Policy and  
Program Specialist



**Janice Fitzgerald**  
Interim Director  
Parent to Parent  
USA



## Objectives

- Increase knowledge of national resources to support parent's engagement
- Highlight how peer support advances person and family engagement and TCPI aims
- Enhance understanding of PCPCC SAN's role and its resources to accelerate TCPI Practice Transformation





- Welcome and Overview of PCPCC SAN Resources TCPI
- Linkage of Peer to Peer Support with Patient and Family Engagement
- Learn About Parent-to-Parent: A National Peer Support
- Review of Available Resources
- Q&A

**How We'll Spend Our Time**





- Review of Patient and Family Engagement (PFE)
- How Peer Support Accelerates Adoption of Key PFE Engagement Strategies

# 'Blockbuster Drug' *Patient Engagement*



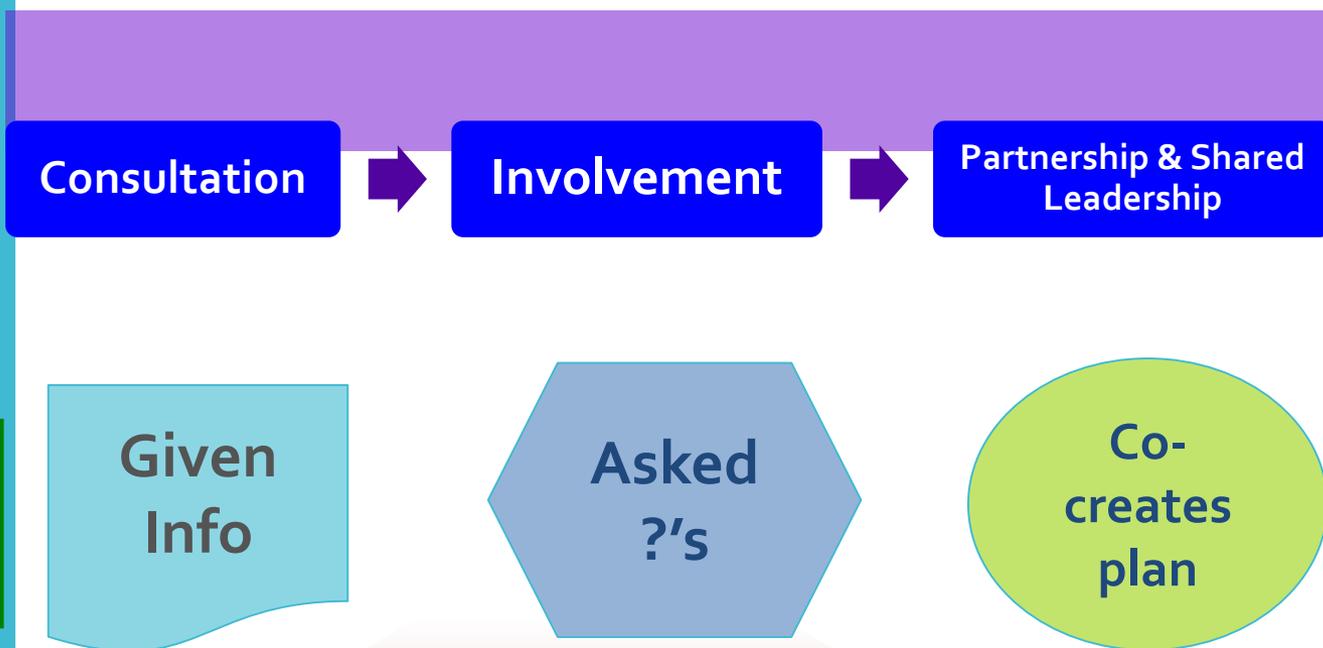
“Engagement broadly defined is an

**active partnership**

among individuals, families, health care clinicians, staff, and leaders to improve the health of individuals and communities, and to improve the delivery of health care.”



# 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



- 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





**P2P USA**  
Parent to Parent USA  
[www.p2pusa.org](http://www.p2pusa.org)

# INTRODUCTION TO THE NATIONAL NETWORK OF PARENT TO PARENT PEER SUPPORT PROGRAMS

Janice Fitzgerald  
Interim Director  
Parent to Parent USA  
[www.p2pusa.org](http://www.p2pusa.org)



# THE IMPACT OF DISABILITY AND ILLNESS



# THE DIAGNOSIS... BREAKING THE NEWS



# WHEN A PARENT LEARNS THEIR CHILD HAS EXCEPTIONAL CHALLENGES

Shock – it didn't make sense, it wasn't supposed to happen to **me**. I took care of myself.

Fear – huge fears. What about my dreams? My employment?

Denial – Acceptance of this situation and life style came ever so gradually. Search for answers, search for treatments, search for cures

Anxiety – How can I reduce my feelings of powerlessness? What do I do to help my child?



# PERCEPTIONS OF DISABILITY

- Disability is viewed with fear, discomfort and loss
- Stereotypes about people with disabilities



# STIGMA OF DISABILITY - HISTORICAL

**Medical model** – person with disability is sick or “disabled” ... excused from typical obligations of society: learning in school, getting a job, taking on family responsibilities, etc.

**Rehabilitation model** - the disability is a deficiency that must be fixed by a rehabilitation professional or other helping professional



# HOW DOES A *NEW* FAMILY RECONCILE?

- How do we reconcile with the messages received and our emotions?
- Perceptions and attitudinal barriers in everyday life bring a sense of isolation.
- Part of the world of disability that has often been perceived negatively.



# BARRIERS & CHALLENGES

- Focus on the glass half empty – the disability, the “can’t do”, the burden
- The words we hear: suffer, courageous, victim, special, crippled, stricken
- Don’t work, criminalized, victimized, exploited, can’t learn, can’t produce
- Laughed at and teased



# EXTRA CREDIT: LEARNING MODULE

## What Do You See? Perceptions of Disability

This Module encourages students to explore their own attitudes and beliefs about people with disabilities. It highlights the abilities of students with disabilities (est. completion time: 1 hour).

<https://iris.peabody.vanderbilt.edu/module/da/>



# HOW DOES A PARENT RECONCILE?

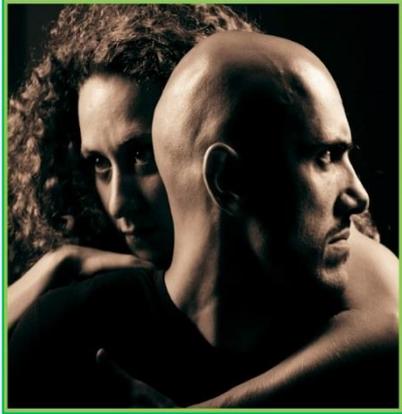
- SURVIVING
- SEARCHING
- SETTLING IN
- SEPARATING



**DR. NANCY MILLER *Nobody's Perfect: Living and Growing with Children Who Have Special Needs.***



# SURVIVING INCLUDES COPING AND REACTING



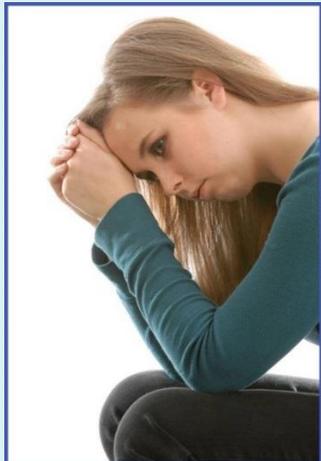
**Denial**



**Anger**



**Shock**



**Grief**



**Fear**



**Guilt**

[Parent's Perspective on Surviving](#)



# STAGES OF ADAPTATION: SEARCHING

## Inner searching

- Asking Life Questions
- Self Discovery



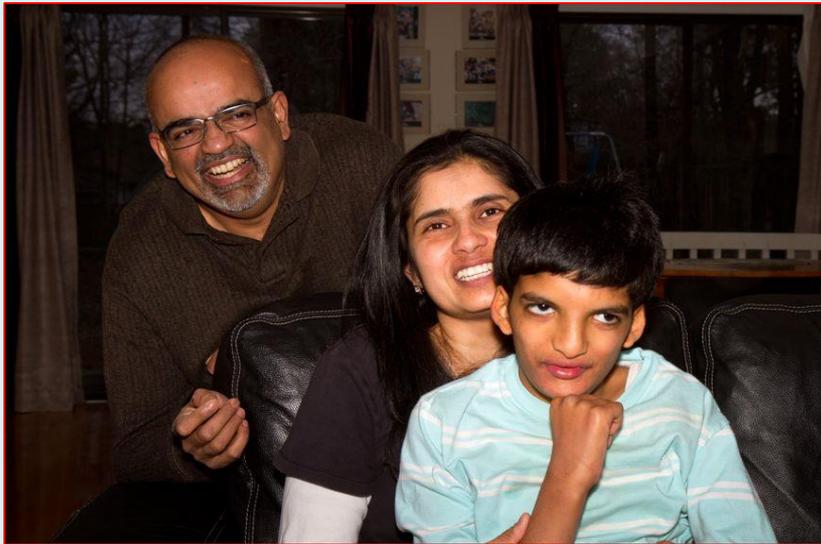
## Outer Searching

- Knowledge
- New Awareness
- Sense of Control



# STAGES OF ADAPTATION: SETTLING IN

- Shift in Attitude: New Normal
- Shift in Balance: New Priorities
- Shift in Control: Assertive and Knowledgeable



## Obstacles

- Continued crisis situation
- Financial Stress
- Relationship stress

[Parent's Perspective on Settling In](#)



# STAGES OF ADAPTATION: SEPARATING



## Process of Separation

- Emotional Separation
- Physical Separation



## Obstacles to Separating

- Child-related Obstacles
- Parent-related Obstacles
- Community Obstacles

[Parent's Perspective on Separating](#)



# ENTER ... PARENT TO PARENT



- Recognize that when a parent's needs are met, they are better able to assist their child in meeting their child's needs
- Grassroots connections in 1970's started local programs. "I can't be the only one, there have to be other parents,"
- Pioneers: Fran Porter, Shirley Dean, Patty McGill, Betsy Santelli
- 2006 National organization formed
- Alliance Members and Community Partners – organizations that operate Parent to Parent programs
- Agree to follow best practices



# PARENT TO PARENT ORGANIZATIONS

Can be stand alone organizations or programs or departments within another organization.

- Employ parents who have experience parenting a child with special needs as coordinators
- Parents are the primary focus; not the person with the disability.



# PARENT TO PARENT

## *Parent to Parent programs offer:*

- One-to-one matches as requested, for emotional support.
- Current information on a variety of disabilities and health issues
- Training for parents who would like to become a support parent
- Training for professionals on how to support families of children with special needs more effectively (some states)
- Information sharing on local, state, and national resources for the child and family, including mothers, fathers, siblings, and others



# PARENT MATCHING: HOW IT WORKS

- Parent is referred to Parent Program Coordinator.
- Coordinator initiates contact with parent gathers pertinent information from parent requesting to be matched with another parent.
- Coordinator locates appropriate match for requesting parent.
- Coordinator contacts the selected Support Parent to see if they can assist the requesting parent.
- Both parents are asked to call their Coordinator after speaking or if they are not able to connect.



# PARENT TO PARENT COORDINATORS AND VOLUNTEER SUPPORT PARENTS



The very best help...the  
very best gift you can give  
to another parent is to  
simply



***LISTEN***



# PARENT TO PARENT COORDINATORS

- Settled in
- Time to take on employment
- Know how to network
- Ask questions
- Accept parents where they are
- Listen



# COORDINATORS

- Create a vision for their future
- Create a parent centered “care plan”
- Ask how the parent is
- Listen and help a parent sort out their questions



# ROLE AND RESPONSIBILITY OF SUPPORT PARENT

## *What does a Support Parent do?*

### The Matched Parent:

- Is experiencing stress
- Is seeking information
- Is usually referred by MP2P

### The Support Parent:

- Is a trained volunteer
- Talks positively
- Shares feelings and experiences
- Is open-minded and doesn't judge!

### The Most Important Things to Remember:

1. The Matched Parent leads the conversation.
2. The Support Parent does not provide all the answers...  
but does provide insight!



# INFORMATION AND REFERRAL

Parent to Parent coordinators do not have all of the answers, but they have developed skills, a knowledge base and a network of connections to assist in helping families access the needed supports and resources.



# PARENT TO PARENT ORGANIZATIONAL MANAGEMENT

Sustainable by contracts and their state's commitment. Financial Support carries the message of value and helps alleviate the burden of putting significant energy into fundraising.

Washington (state) has a commitment in 'State Statute' to have family support from Parent to Parent in all counties by 2020.



# HOW TO KEEP FAMILIES ENGAGED?

State Programs offer:

- Webinars
- E-groups for sharing Information
- Continuing Education – a ‘translate’ button for the language of service systems



# PARENT TO PARENT

*We want the best for our children, but how do we also focus on keeping ourselves (parents) at our best? Family Support is crucial.*

You can't pour  
from an empty cup  
take care of yourself first.



Thank  
You!

- Mary Minniti Senior Policy and Program Specialist, Institute for Patient- and Family-Centered Care  
541-520-3655

[mminniti@ipfcc.org](mailto:mminniti@ipfcc.org)

- Janice Fitzgerald, Interim Director, Parent to Parent USA 518-637-9441

[parenttoparentusa@gmail.com](mailto:parenttoparentusa@gmail.com)





# Resources to Support Your Patient and Family Engagement Efforts

# 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 Asset

PCPCC has a set of strategies, tools, and resources that are used by practice coaches to engage clinicians in Person and Family Engagement (PFE) transformation

PTNs receive support through:

- Customized trainings and direct technical assistance to PTN practice facilitators and sometimes to clinicians
- Coaching from subject matter experts in PFE implementation
- Unlimited access to our Person and Family Engagement Resource Library
- Learning networks: Pediatric Asthma and PFE Learning Network

Trained practice facilitators integrate PFE in their QI coaching



With support from coaches, clinicians effectively integrate PFE activities into transformation to amplify progress on cost and quality goals.



# The PCPCC SAN: Our Partners

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COLLABORATIVE



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Member of the Parent to Parent USA Alliance,  
Committed to Parent to Parent USA-Endorsed Practices



*An initiative of the ABIM Foundation*



**TCPi** | Transforming Clinical  
Practice Initiative



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

The screenshot shows the Patient-Centered Primary Care Collaborative website. At the top left is the logo. A navigation menu includes: About Us, The Medical Home, Priority Issues, Membership, Resources, Events, and News. Social media icons for RSS, Facebook, Twitter, and LinkedIn are visible. A search bar is present. The main content area features a purple header with the text "Improving Care Through Partnership with Patients, Families & Communities". Below this, a blue box contains text about the Support & Alignment Network (SAN) and its funding by CMS through the Transforming Clinical Practice Initiative (TCPI). A "Learn More" link is provided. Three icons represent "Patients & Caregivers", "Clinicians & The Care Team", and "Administrators & The Qi Team".

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



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!

Please contact us if you have questions or want more information:

- Merilyn Francis, Project Director  
[mfrancis@pcpcc.org](mailto:mfrancis@pcpcc.org)
- Tanya Thabjan, Program Manager  
[tthabjan@pcpcc.net](mailto:tthabjan@pcpcc.net)

