Strengthening Patient and Family Engagement Through Parent to Parent Support

Webinar
September 21, 2018
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
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
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
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
“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.”

Health Affairs, 32(2) 2013
Continuum of Patient Engagement

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
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 are the Benefits to the Patient or Family Member?

Practice, 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
- Knowledge from education and training
- Support via counseling, problem-solving, skill development training

Peer Supporter

Professional
Integrating Peer Support into Practices

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

Janice Fitzgerald
Interim Director
Parent to Parent USA
www.p2pusa.org
THE IMPACT OF DISABILITY
AND ILLNESS

Parent to Parent USA
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 lifestyle 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 USA
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.
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
We want the best for our children, but how do we also focus on keeping ourselves (parents) at our best? Family Support is crucial.
Thank You!

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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](http://www.pcpcc.org/tcpi)
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.
Webinars, Tools, Resources to Strengthen Your PFE Efforts!

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.

http://pfcc.connect.ipfccc.org/home
THANK YOU!

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

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