Engaging Patients, Caregivers and Peer Support for Primary Care Transformation

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Peer Care Coordination Project

RI PARENT INFORMATION NETWORK (RIPIN)
2003

Pediatric Practice Enhancement Project (PPEP)

The PPEP was developed in 2003 to assist and support pediatric primary and specialty care practices in providing improved short and long-term health outcomes for CYSHCN and their families within a medical home. The project places and supports trained Peer Resource Specialists in clinical settings to link families with community resources, assist physicians and families in accessing specialty services, and identify systems barriers to coordinated care. The primary role of the Peer Resource Specialist is to create linkages between the family, pediatric practice, and the community as a whole.
Why the PPEP Project works

The PPEP model successfully demonstrated that utilizing a paraprofessional to reinforce healthcare messages, provide patient education and deliver care coordination is more cost effective than utilizing a licensed clinician, i.e., a nurse or social worker. Furthermore, a paraprofessional matched culturally and linguistically is found more effective in improving health outcomes.
Due to the success of the PPEP project, RIPIN’s Peer Care Coordination Project was born.

In January 2015, RIPIN partnered with Rhode Island Foundation to conduct a one-year pilot, showcasing the Peer Care Coordinator role in two pediatric settings. Utilizing a Peer Care Coordination tool, developed by Dr. Richard Antonelli of Boston Children’s Hospital, this project was designed to capture and categorize all care coordination activities at each site into clinical and non-clinical supports.

The Peer Care Coordination project assists in providing a “Medical Home” for Children and Youth with Special Health Care Needs (CYSHCN) and their families to improve short and long-term health outcomes.
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WHAT IS A PEER CARE COORDINATOR?

- A Peer Care Coordinator is a parent or family member that has navigated the system of care for their child/youth with special health care needs and assists families going through similar situations.

- The Peer Care Coordinator assists physicians and families in accessing specialty services and identifies systems barriers to coordinated care. A Peer Care Coordinator provides non-clinical support and assistance to Nurse Care Manager’s or the primary care provider (PCP). Through our contract with the RI Foundation, the Rhode Island Parent Information Network (RIPIN), a non-profit family advocacy organization, conducts the recruitment, hiring, training and supervision of Peer Care Coordinators.
RIPIN Peer Care Coordination aims to enhance provision of coordinated and comprehensive care, recognize families as critical decision makers, and increase family understanding of health care delivery systems and community resources.

The integration of peer support through Peer Care Coordinators helps fill gaps in the Medical Home that were previously cited by providers (e.g. lack of time to address non-clinical issues, program eligibility, and knowledge of resources within families communities to provide a higher satisfaction from patients and their families.

The goal of our project is to demonstrate the time commitment that is needed by a multi-disciplinary team to facilitate successful comprehensive clinical care coordination. Also, at project end, we aim to document clinical vs non-clinical use of staffing to determine if the provided coordination is relevant to the clinical competence of the professional providing the service, ie: a doctor or nurse case manager assisting with a housing issue.
RIPIN is nationally known and valued for our innovative “Peer Care Coordination” programs. This model engages peers to help caregivers and individuals with special needs successfully access health coverage, navigate health care and educational systems, as well as providing other much needed assistance to improve social determinants of health.

RIPIN has a long standing reputation in assisting the community with improved empowerment. At the conclusion of the project, we will survey families who have collaborated with a RIPIN Peer Care Coordinator to determine if the higher level of supports that they received helped reduce stress, improved the patient/family experience, and helped them achieve better health outcomes through individualized care coordination, utilizing a multi-disciplinary approach.
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INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

www.ipfcc.org
Patient- and family-centered care is working "with" patients and families, rather than just doing "to" or "for" them.
Where is your practice?

Are there opportunities for patient and family advisors to partner with the practice in:

- Practice Transformation and the development of a PCMH?
- Quality improvement and safety initiatives?
- Developing, improving, and evaluating care processes, including systems for care coordination, care transitions, and supportive services for those with complex needs?
- Developing, implementing, and evaluating the electronic health record and patient portal?
- Developing peer support and community connections?

Are there opportunities for patient and family advisors to partner with the practice in educating staff and trainees and in research and evaluation?
Patient-Centered Medical Home Brochure

- Created in partnership with Patient & Family Advisors, Providers, Health Educators.
- Translated into 5 languages and has patient’s clinic information on the back.
- Used “real people” in brochure – Advisor in the center.
We will be ready for our visit together.

"I will make a list of one to three most important things to talk about."

"I will make sure your biggest health concerns are addressed."

We will honor each other’s time.

"I will arrive 15 minutes early in case I need to fill out papers or have any tests."

"My staff will tell you if I’m taking longer than expected with other patients."

We will recognize each other’s needs.

"I will bring my health plan ID and anything else needed to provide my care."

"I will recognize that you may have other needs, such as transportation."

We will focus on one to three priorities.

"If I have more issues, I’ll make another appointment."

"I’ll help you set priorities for our visit, and assure you we can meet again."

We will agree on a treatment plan.

"If I have any questions about my health or my plan, I will ask you to explain."

"I will give you a written plan, and be sure you are comfortable with it."

We will be open.

"I will find out what any tests or lab results mean."

"I will help you understand your test results and my diagnosis."

We will talk honestly.

"I will try to understand the risks and benefits of each medical option."

"I will recommend options, including preventive measures and lifestyle changes."

Care Oregon…partners with members for improvement
Supporting Collaboration in the Office Visit

What I need most from my appointment today:

1. 
2. 
3. 
4. 
5. 

Additional thoughts or comments:
After Visit Summary Subcommittee

- 5 monthly 2-hour meetings
  - 7 Patient & Family Advisors,
  - Sr. Regional Medical Director,
  - Health Educator, Provider Educator
  - Program Coordinator

- AVS Data collected for baseline
- Poster created
- Communication plan developed
Patient & Family Advisors presented to leadership, all clinic managers and medical directors, 3 months later. . . 

the use of the after visit summary increased by 29.29%

“This is remarkable work! It shows the power of engaging our patients in quality improvement work as partners.” - Dr. Ben LeBlanc, CMO
Providence Medical Group, Portland, OR
Patient and Family Work on Patient Portal

Showing the work of patient and family advisors.
Silver Avenue Family Health Center
San Francisco, CA

Patient and family advisors with the staff liaison

Working together to make clinic changes and improvement and engage in peer support.
Patient advisors participate in the self-management support communications training with physicians and staff.
“Patient and Family advisors – culturally this was a change to the organization. The value they brought has been huge.”

“. . . the patient advisory group [concept] seemed to gain a lot of traction. It also has been the most rewarding piece.”

“We did not expect how much of a difference the patient advisors would make. It was a huge effort but we saw value in making patient advisors part of the process.”

“Patient advisors are invaluable and are now used in other areas.”

http://www.teamupforhealth.org/
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Engaging Family Caregivers in Primary Care Transformation

Gail Gibson Hunt
President & CEO, National Alliance for Caregiving
November 11, 2015

@NA4Caregiving
About the Alliance

• 501(c)(3) non-profit coalition founded in 1996

• Our mission is to advance family caregiving through research, innovation, and advocacy

• Activities include conducting public policy research, building state/local caregiving coalitions, & increasing awareness of family caregiving issues in the U.S. & around the world

NAC President & CEO Gail Gibson Hunt presenting at the White House Conference on Aging Caregiving Summit on May 18, 2015 (pictured at center)

www.caregiving.org
Four key points:

• Caregivers are more than an “intervention” to help the patient – they have separate needs

• Clinicians should assess the (1) willingness and (2) ability of the caregiver to participate in the healthcare team

• When willing and able, healthcare providers should include family caregivers in the medical records

• Family caregivers need training and support on medical/nursing tasks
Needs Align – But They’re Not Identical

**Patient Needs**
- Information about the disease, self-care
- Access to treatment
- Access to clinicians
- Quality of Life
- Improved health or delayed onset of disease
- Autonomy, shared-decision making
- Financial, emotional support

**Caregiver Needs**
- Information about how to provide care
- Inclusion in the healthcare team
- Workplace flexibility
- Respite care
- Support for medical tasks, activities of daily living
- Financial, emotional support
Assess Willingness & Ability to Care

• Choice Matters
  – Caregivers who report having “no choice” in taking on the role report higher rates of emotional stress, financial strain, and burden and report worse health

• Caregivers may be willing, but unable to help
  – Think of the 78 year old spouse who is being asked to lift and bathe her husband

Include Caregivers in Medical Records

• When willing and able, include family caregiver contact information, discharge instructions in medical records

• Policymakers know this would help:
  – Meaningful Use Stage 3 will include caregivers in EHRs, but implementation is delayed
  – State legislation known as the C.A.R.E. Act includes caregivers in records at hospital discharge, now law in 18 states
Provide Training on Medical Tasks

• 8 out of 10 high-intensity or “higher-hour” caregivers conduct medical and nursing tasks with no prior preparation.

• Caregivers in the most complex care situations are the ones most likely to be performing medical/nursing tasks without any preparation.

• Training protects the safety of the patient and reduces caregiver stress!

Thank you!

Gail Gibson Hunt
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