Patient Navigation
Care Coordination Meets Peer Support

TUESDAY, AUGUST 2, 2016
12 – 1PM EST

Sarah Roth, MFA, Genetic Alliance
Brad Thompson, MA, Parent Partner Project
Pattie Archuleta, Parents’ Place of Maryland
Jodie Vento, MGC, LCGC, Center for Rare Disease Therapy
Michelle Jiggetts, MD, Children’s National Medical Center
Today’s Webinar

- Needs & Navigation
- Vision for the Future
- Models Represented
  - Parent Partner Project - Amarillo, TX
  - Parents’ Place of Maryland - Glen Burnie, MD
  - Center for Rare Disease Therapy - Pittsburgh, PA
  - Children’s National Medical Center - Washington, DC
- Discussion
Complex Care Needs

- Children and Youth with Special Health Care Needs
- Individuals with Serious or Chronic Conditions
- Individuals with Genetic Conditions
- Underserved Communities
Addressing Gaps in the System

Support
Coordination
Empowerment

Quality

Patient Navigation

Access
Patient Navigation

A process by which an individual—in the role of patient navigator—guides patients through and around barriers in the complex care system.

- Est. 1989 by Harold P. Freeman in Harlem, NY
- Activities include support, coordination, empowerment
- Diverse programs sprawl across the country
Models of Navigation

- Peer Support Program
- Parent Advocacy Network
- Disease Advocacy Organization
- Promotores de Salud
- Consumer Advocate
- Health Coach
- Nurse Navigator
- Parent Navigator
NEXT STEPS TOWARD PATIENT NAVIGATION
Perspectives from Partners in Care
Envisioning the Future
Envisioning the Future

Goal: Holistic patient navigation and support i.e. Put the person and their needs at the center of their healthcare.

What’s Needed:
1) Research
2) Coordination
3) Infrastructure
The Hali Project: Innovative and Promising Practice in Pediatric Medical Home Implementation

BRAD THOMPSON, MA, LPC
CO-FOUNDER, THE HALI PROJECT
BTHOMPSON@SOUTHWEST.ORG
WWW.THEHALIPROJECT.ORG
806-352-5647 OR 806-676-1773
The HALI Project Model

The original question:
“How can we take the “nonmedical pieces” of family-centered care off of the provider’s plate?”

What are those things?
• Local services – both traditional and non-traditional
• School challenges
• Emotional challenges
  o “This is not the way it’s supposed to be”
  o “You’re not alone”
  o “My spouse/parents/in-laws think he just needs a spanking”
1. Emotional stress associated with caring for CYSHCN
2. Access to high quality, coordinated care
3. Time spent accessing care & services
4. High costs associated with CYSHCN – in all areas of life

OBJECTIVE

Help providers identify potential parent partners who can provide the non-medical aspects of the medical home model.

GOALS

1. Preserve, strengthen, and support family members as they care for loved one
2. Provide on-site access to resources, allowing providers to operate more efficiently.
3. Provide empathy for caregiver’s stress.
4. Encourage hope
5. Create savings to the system.

ACTIVITIES

1. Clinic staff identifies potential Parent Partners
2. Train Parent Partners using Hali Project Training curriculum.
3. Provide ongoing relational support between clinic visits.
4. Identify family stressors.
5. Provide caregivers access to services and information.

OUTPUT MEASURES

1. Parent Partner training and ongoing support from Program Director.
2. Improved patient/family engagement experience.
3. More comprehensive, onsite resources for providers
4. Reduced wait time
5. Improved provider satisfaction.

OUTCOME MEASURES

SHORT-TERM

1. Reduced family stress levels.
2. Improved treatment plan compliance.
3. Reduced time spent during clinic visits.
4. Decline in the number of emergency room visits.
5. Improved connections to local support groups.

LONG-TERM

1. Improved quality of care
2. Better patient/family outcomes.
3. Reduced healthcare costs.
4. Higher quality comprehensive, family centered care.
5. Improved satisfaction for patients, families, and providers.
Benefits of the Parent Partner Model

1. We reduce the cost of “the listening ear.”
   - Unbillable hours
   - By having these conversations, Parent Partners pay for themselves.
2. Moms will tell another mom they trust things they will never share with anyone else.
3. Parents with experience in the world of special needs know who to talk to, not just what number to call.
   - This saves everyone’s time
4. Parent Partners are far more available between office visits.
   - Encourages better follow up and follow through.
   - Can produce better insight into a family’s life.
The HALI Project Parent Partner Model

Benefit to Families

- Gives them someone who’s “been there.”
- Gives them someone they can talk to away from the doctor’s office.
- Gives them support away from the office in other complicated areas of life.
- Gives them not only the “where” but the “who.”
The HALI Project Parent Partner Model

Benefits to Providers:

- Reduces the cost of the “listening ear.”
- Allows you to spend more time “at the top of your license.”
- What are the things you do regularly that are time consuming and not reimbursable?
HELPING FAMILIES OF CHILDREN AND YOUTH WITH DISABILITIES AND SPECIAL HEALTH CARE NEEDS

The Parents’ Place of Maryland
MAKING CARE COORDINATION WORK:
Parent Partners in the Medical Home

Pattie Archuleta

*Family Health Information Center Project Coordinator*
*Medical Home Parent Partner Program Coordinator*

THE PARENTS’ PLACE OF MARYLAND

SUPPORT | INFORM | EMPOWER
A: Autism and Developmental Disabilities
   Screening and BEYOND

B: Epilepsy and Seizure Disorders
   Primary Care Enhancement

C: Maryland Transitioning Youth
   Epilepsy and/or Autism

IMPROVING CARE IN PEDIATRIC PRACTICES

Quality Improvement Learning Collaboratives
Thanks to our Project Partners!
PRACTICES
- Input regarding challenges families experience
- Meaningful family engagement – continuous support and feedback
- Information on community and state resources

FAMILIES
- Family “voice” represented at the table for all CYSHCN
- Targeted case management and system navigation
- Support, resources, information – empowered

OVERALL
- Improve communication and partnership between families and staff
- Data show better health outcomes for children & families
- Recruited, hired, and placed by outside organization into a medical practice
- Paid/short-term placement
- Working with more than one practice on THREE initiatives
- Participate in QI Learning Collaborative AND provide follow-up information, care plans, and support to families and staff in practice
Veteran parents of CYSHCN have an extremely rich and valuable perspective.

- Have time to commit (access to childcare, etc.)
- Emotionally ready to look outside of themselves and family
- Enjoy working as part of a team – fit well into a group dynamic
- Experience with community-based resources
- Experience with multiple specialists
- Able to share their personal story in a meaningful way
- Confident and able to speak up in group settings
- Good listeners and communicators
- Family/Professional Partnerships
- Community-based Resources
- Cultural Competency
- Quality Improvement
- HIPAA Compliance
- Data Collection
- Medical Home
- Medical Assistance
- Epilepsy/Autism Bootcamp
- Early Intervention
- Transition to Adult Healthcare
- On-going training and support
Parent Partners are equal members of the Quality Improvement team!

- Participate as a member of the Medical Home QI Team
- Meet with Medical Home QI Team on a regular basis
- Provide input on changes as part of PDSA process
- Participate in QI Learning Collaborative
- Assist in implementing PDSA process
- Provide follow-up and resources
- Collect and report data to project
- Administer the **MHI**
How It Works

Helping physicians to provide a more comprehensive Medical Home

- When a provider learns or suspects that a patient has needs beyond the medical scope of the practice, the family is referred to the Parent Partner.

- Parent Partner talks with the family regarding their concerns and develops a plan to address the family’s needs.

- Parent Partner links families with community resources, helps providers and families navigate specialty services, and identifies systems barriers to coordinated care.
Parent Partners provide support and resources to families of CYSHCN and pediatric practice staff:

- Resource identification
- Community referrals for social, developmental, or mental health services
- Links to the Special Education system including free IEP support
- Eligibility or application assistance for health insurance or other services
- Navigation across services
- Peer-to-peer support
- Care notebooks
- Seizure action plans
- Developmental screening follow-up
- Identify family resource needs and provide referral
- Resource referral follow-up
- Share resources with practice staff

* Parent Partners do NOT provide clerical help
Promoting Parent Partners

- Mail letter with consent form
- Distribute and post fliers

Referrals to Parent Partners

- Families of children with failure or borderline results on Developmental or Autism Screen
- Families of children with epilepsy
- Families of transition-age youth
- Families of ANY CYSHCN who could benefit from additional guidance and support
- Education
- Emotional Support
- Behavioral Health
- Referrals & Follow-up: evaluations, specialty providers, early intervention
- Health Insurance
- Practices hire Parent Partner directly
  - Explore the use of Care Coordination billing codes
- Block grant from Maryland Title V – funded for 3 years!
- Written into next round of HRSA/ASD grant funding
Challenges

- Challenges of data collection
- Integration of Parent Partner into practices
- Staffing issues
- Not enough face time
- Lack of space, support, technology
- Statewide challenges
Center for Rare Disease Therapy – Patient Navigation

Jodie M. Vento, MGC LCGC
August 2, 2016

Children's Hospital of Pittsburgh of UPMC

Center for rare disease therapy
• Needs assessment → rare diseases are currently underserved in large medical systems, need a comprehensive rare disease center
• Focus on research, education, therapy, and patient coordination
Center for Rare Disease Therapy

International experts focused on treating children with rare diseases, defined by leading standards of care, pioneering protocols, and individualized services in a world-class environment.

For more information, visit chp.edu/rarecare 412-692-RARE (7273)
Core Components

Education
- Conferences
- Website/Marketing

Research
- Pioneering new protocols
- Funding innovative therapies

Collaboration
- Leading standards of care
- Multi-disciplinary care
- External partnerships

Clinical Care
- Knowledgeable Liaisons
- Patient coordination
- Funding to improve access
Navigator Responsibilities

- Answer calls/emails within 24-48 hrs
- Identify protocol or pathway for the patient
  - Create new protocols if needed
- Take time to connect w/ family and ensure needs are addressed
- Gather records and prepare a summary for the team
- Coordinate appointments
- **Ensure team is on the same page**
- See the patient/family during their visit(s)
- Follow-up after appointments
CRDT Dashboard

- **Success is measured differently by all stakeholders!**
  - Referral #s and sources
  - Financials
  - Tracking marketing intervention
  - Reviewing quality data over time
  - Engaging families for feedback and program development – patient advocacy/advisory board
  - Outcome data
Lessons Learned

- Engage key stakeholders upfront
- Development a mission
- Outline steps to achieve mission/goals
- Ensure that program is considered an important priority by your organization
- Elicit on-going feedback
- Be receptive to change
- Be creative!
The Parent Navigator Program

August 2, 2016
Genes in Life
Genetic Alliance Webinar

Michelle Jiggetts, MD, MBA
Parent Navigators:
Bridging the gaps between patients and families and the health care system
Parent Navigator Program: Our History

- Piloted in 2008
- Founder: Cara Biddle, MD, MPH
- Initial support from DC DOH
  - Community Health Administration
- Continued support from State of MD-DHMH (OGPSHCN)
- CYSHCN focus
- Peer mentors
- Customized service
- Serves families in DC, MD and VA
Program Mission

• Provide non-medical assistance and support to families of children with chronic medical conditions and special health care needs
• Seek to inform, educate, support and advocate for families of children with special health care needs
• Empower families to be strong partners with their providers while providing guidance for families to advocate for themselves — developing “Legacy Families”
Our Team

- Initially 2 parent navigators (P/T)
- Increased to 6 full-time navigators – Two bilingual
- Hospital employees
- All parents of children with special needs
- Members of the health care team in primary care and Complex Care Program
- Serving in 6 of our NCQA Level-3 certified medical homes
Roles and Responsibilities

- Based on Pediatricians and Family Needs
- Provide Peer-to-Peer support
- Coach families on how to advocate for their child
- Help families to communicate more effectively with health care professionals
- Link families to community and educational resources
- Work with families to understand their educational rights and responsibilities (e.g. IFSP, IEP)
- Prepare families for transition
- Provide follow-up with families to ensure needs are met
Parent Navigator: A Key Member of the Medical Neighborhood

- Parent Navigator
- Inpatient Care Team
- Insurance Case Manager
- School Nurse
- Specialty Physicians
- Parent Navigator
- Private Duty Nurse
- Community Therapists
- Primary Care Medical Home
PN - Patient Satisfaction Survey

- Patient Satisfaction surveys are disseminated to families bimonthly.
- In FY 2015: More than 95% of parents surveyed were satisfied with their Parent Navigator Program experience, felt it was helpful, and would recommend it to other families.
- REACH Project: 2 & 3rd year residents evaluate utilization and effectiveness of the PNP.
- Evaluate impact of Parent Navigation on mental health outcomes for caregivers of infants being discharged from the Neonatal Intensive Care Unit, with current PCORI funding. Dr. Karen Fratantoni, PI
Lessons Learned

• Identifying and securing continued funding
• Building and maintaining infrastructure
  – Data systems
  – Staffing schedules
• Standardizing parent navigation services hospital-wide
  – Specialty clinics with different versions of navigation
• Maintaining professional boundaries
• Overcoming communication barriers
  – Ineffective language interpretation
  – Lack of staff sensitivity to literacy levels and unique dialects
  – Cultural differences
• Maintaining employer flexibility
• Identifying certification programs
• Integrating social media
Distinguishing Features

- Parent Navigators are 100% benefitted employees
- Navigators are fully integrated into our medical health care team
  - Trust developed between provider and PN
  - Providers feel they are more effective in caring for CSHCN
- Navigators actively participate in leadership and hospital committee meetings to communicate parents perspective
- Families trust and are comfortable with the PN
- Development of ‘Legacy Families’ - Helping families to become better advocates for their child
Thanks

Questions and Answers
Discussion

Questions?
Contact Information

**Sarah Roth**, Genetic Alliance
Health Program Coordinator
sroth@geneticalliance.org

**Brad Thompson**, Parent Partner Project
Founder and Director
bthompson@southwest.org

**Pattie Archuleta**, Parents’ Place of Maryland
Medical Home Parent Partner Program Coordinator
pattie@ppmd.org

**Jodie Vento**, Center for Rare Disease Therapy
Manager, Center for Rare Disease Therapy & Brain Care Institute
jodie.vento@chp.edu

**Michelle Jiggetts**, Children’s National Medical Center
Parent Navigation Program Administrator
mjiggett@childrensnational.org