





Care Coordination Welcome and Overview

Facilitator: Pat Flanagan, MD

Date & Time: Wednesday, May 31, 2023

PLEASE NOTE: Project ECHO case consultations do not create or otherwise establish a provider-patient relationship between any clinician and any patient whose case is being presented in a project ECHO setting

Care Transformation Collaborative of RI







Time	Topic	Presenter
7:30 AM – 7:35 AM	Welcome	Pat Flanagan, MD CTC-RI
7:35 AM – 7:45AM	Project Introduction Overview and What is ECHO?	Pat Flanagan, MD CTC-RI
7:45AM – 7:50AM	Faculty Introduction	Pat Flanagan, MD CTC-RI
7:50AM – 8:55AM	M – 8:55AM Didactic and Case Presentation: Family Voice & Tara Hayes and Stephanie Trafl Entitlement to Eligibility RIPIN	
8:55 AM – 9:00AM	Wrap up; Evaluation; Announcements	Kim Nguyen-Leite CTC-RI







Please note that the didactic portion of an ECHO session will be recorded for educational and quality improvement. The case presentation portion of an ECHO session will never be recorded.

Remember to never disclose protected health information (PHI), verbally or in writing, to preserve patient confidentiality.

We are participating in an open and welcoming learning environment. Thank you for generously sharing your knowledge and experience so that all can benefit from it!









Mute your microphone when not speaking



Limit distractions as best as possible.



Use reactions & the raise hand feature.



Engage and turn on your camera, if you are able.



Use the chat to introduce yourself, ask questions and share resources.



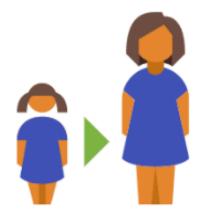
Engage - ask questions, offer feedback, provide support.







Focus on strategies to improve care coordination for families with young adults, with special healthcare needs, transitioning from pediatric to adult care.



















Care Coordination Planning Team



Colleen Polselli
Special Needs Program
Manager
Office of Special Needs
RI Department of
Health



Susanne Campbell, RN, MS, PCMH CCE Senior Program Administrator, CTC-RI



Pat Flanagan, MD
Clinical Director and
PCMH Kids Co-Chair,
CTC-RI



Sue Dettling, BS, PCMH CCE Program Manager & Practice Facilitator, CTC-RI



Kim Nguyen-Leite, MHA, CPHQ, PCMH CCE Program Coordinator & Practice Facilitator, CTC-RI

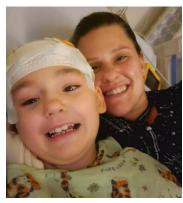


Tara Hayes, BS, CCHW RIPIN Family Voices Manager





Care Coordination Planning Team



Stephanie Trafka, CCHW RIPIN Family Voices Health Research Support Specialist



Kathleen N. Kuiper, BS, CCHW RIPIN Resource Coordinator



Allison Brindle,
MD, FAAP
Director, Center for
Children with
Medical Complexity,
Hasbro Primary
Care



Susan Jewel

Manager of Family

Support

The Autism Project



Carol A. Musso, RN, BSN Care Specialist United Healthcare



CPRS
Executive Director
Parent Support
Network of Rhode
Island





Care Coordination Planning Team



Erika lafrate, BSN, RN, NCSN State School Nurse Consultant Rhode Island Department of Health (RIDOH)



Gail Davis, RN
Program
Administrator at
Hasbro Primary
Care Medicine
Pediatrics



Jennifer Kaufman
Chief of Family Health
Systems



Rosemary O'Brien
Health & Wellness
Specialist
NHPRI



Susan Hayward
Administrator, Youth
in Transition
Division of
Developmental
Disabilities, BHDDH









Center family and patient strengths and goals for care coordination in transitions



Use technology to create a learning community



Share best practices and resources to reduce disparities



Use case-based learning to increase knowledge







- Introductions/Housekeeping (5 min)
- Lecture (followed by short Q&A) (15-20 min)
- De-identified Case Discussion (25 min)
 - Case Presentation by spoke or faculty
 - Facilitator summarizes case; asks for clarifying questions
 - Recommendations/Discussion
 - Facilitator summarizes recommendations
- Wrap-up (5 min)

ECHO sessions are shorter than the typical webinar to allow for more active participation. Much of the learning is done through discussion.







Date	Speaker(s)	Topic
5/31/2023	Tara Hayes and Stephanie Trafka, RIPIN	Family Voice & Entitlement to Eligibility
*7:30am – 9am		
Thursday,	Jeannine Casselman, MLPB	Guardianship
6/29/2023		
7:30am – 8:30am		
7/26/2023	Susan Hayward and Denise Achin, BHDDH	Understanding BHDDH/ Developmental
7:30am – 8:30am		Disability Transitions of Care
8/30/2023	Adam Pallant, Brown University	Care Coordination for Children with Special
7:30am – 8:30am		Healthcare Needs in College
9/27/2023	Lisa Guillette, Foster Forward & Joan	Supporting Youth in Foster Care & DCYF
7:30am – 8:30am	Harmon, DCYF	
10/25/2023	Carol Musso, UHC	Durable Medical Equipment & Resources
7:30am – 8:30am		
11/29/2023	Susan Jewel, The Autism Project	Autism
7:30am – 8:30am		







- Please provide us your feedback!
- Evaluation/Credit Request Form : https://www.surveymonkey.com/r/CCECHOCME2023



Please request CME credits or a certificate of participation when filling out the evaluation at the end of the meeting.

Application for CME credit has been filed with the American Academy of Family Physicians. Determination of credit is pending.







Care Coordination ECHO Session Topic: Family Voice & Entitlement to Eligibility

Facilitator: Pat Flanagan, MD

Faculty and Case Presenter(s): Tara Hayes and Stephanie

Trafka

Date & Time: Wednesday, May 31, 2023 @ 8am

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 - Please turn on your video
 - Please enter your name and organization in the chat box

Introduce Yourself



 Please mute your microphone when not speaking

Microphones

- Introduction
- Lecture
- Case/Discussion
- Close

Agenda





About the presenters:



Tara Hayes, RIPIN Family Voices Manager - Tara is the mother of 3 children: Andrew, 15, who is has an undiagnosed neuromuscular condition which keeps him very limited in a physical capacity; Shamus, 11, and Grace, 7. Tara has expertise in dealing with systems of care for medically fragile children, as she has been caring for her son Andrew who is trached, on a ventilator, g-tube fed, and non-ambulatory. She has been working for RIPIN for more than 12 years. In her role, she assists families with children with special health care needs to receive family-centered care, access services available to them and help them advocate at the local, state and national level to create policies and awareness around needs and accessibility. Tara sits on numerous committees and workgroups providing the parent perspective and advocating for families to create better outcomes. In November of 2018, she was awarded RI Caregiver of the Year for her role as a mother to Andrew and her tireless advocacy for all RI families. She holds a Bachelor of Science Degree in Special Education and previously taught at Toll Gate High School.



Stephanie Trafka, RIPIN Family Voices Health **Research Support Specialist** – Stephanie is a mom of 2 active young boys: Brayden, 8, and Gavyn, 10, who has a diagnosis of KCNB1 genetic syndrome, presenting with refractory epilepsy, intellectual disability, and significant behavioral challenges. Stephanie has extensive experience navigating multiple systems of care for children with complex medical and/or developmental-behavioral needs, as she has been the sole caregiver for both Gavyn and Brayden for most of their lives. Stephanie has been working for RIPIN for over 5 years. In her current role with Family Voices, Stephanie assists families of children and youth with special healthcare needs in navigating various systems of care, as well as helping to advocate for policy change at a local and state systems level on behalf on her family and the families RIPIN serves. Before coming to RIPIN, Stephanie worked directly with individuals of all ages and abilities as a Certified Therapeutic Horseback Riding Instructor. She has held this certification since 2016 and has also been a Certified Community Health Worker here in Rhode Island since 2019.

RIPIN

Entitlement to Eligibility



PERSONAL SUPPORT BUILT ON PERSONAL EXPERIENCE

Disclosures

Session presenters have no financial relationships with a commercial entity producing healthcare-related products used on or by patients.

If CME credits are offered, all relevant financial relationships of those on the session planning committee have been disclosed and, if necessary, mitigated.



Key Objectives:

- Case presentation will highlight a family's real-life experience and challenges with the transition from pediatric to adult healthcare services for their child with complex healthcare needs.
- Facilitate an open discussion around the process of transition from pediatric to adult healthcare services and supports (entitlement to eligibility), what's involved, opportunities for improvement, and what both families and professionals need to know.
- Identify key priorities for many families as well as barriers to obtaining the necessary supports throughout and after this transition.
- Outline how developing a partnership with RIPIN can help families and professionals navigate these systems together, providing continuity of care for all individuals in need.





Parent Testimony

Leanner Et Zack Quin Zack Quin

"All my child did is do what he was supposed to do....Grow Up."



2019 RIPIN Policy Forum:
Access to Care



Case Presentation & Discussion

Why did we select this case?	This case provides a real-life snapshot of the lived experience and challenges a family faces when caring for a child with complex medical needs.
Goals for this case presentation:	 Hear first-hand the challenges families with children/youth with complex needs face during transition. Know who you can call with questions. Learn resources available to families and professionals. Develop a partnership with RIPIN.
What questions do you have for the group?	 What could be done to ensure continuity of care for families during and after transition? What resources are available to families that medical professionals may not be aware of?



What goals does the patient have?

- Optimal quality of life overall.
- Maximum independence in day-to-day activities.
- Continuity of home nursing care to ensure health & wellness.



What goals does the family/caregiver have?

- Coordinated healthcare services that will evolve and grow with him appropriately as he ages.
- A team of professionals that can help ensure proper coordination of services throughout transition to adulthood and beyond, thus easing the burden on the family.



RIPIN: A One Stop Shop for Connections to Services and Support

- Early Intervention
- Cedar Family Center
- Family Voices
- Parent Training Information
 Center (PTIC)
- Call Center
- Community Health Network
- Care Management



Gateway to Information: RI Medical Home Portal



- For Physicians and Professionals
 - Navigating Transitions (for Professionals)
- For Parents & Families
 - Navigating Transitions with your child (for Families)
 - Care Notebook
 - Provider Directory



Additional resources to help support families

<u>RIPIN</u>

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- Connecting the Dots Resource Guide
 - Pathways to Adulthood Transition Navigation Checklist
- Support Groups Flyer



BHDDH - A Young Adult's Guide to RI's Behavioral Health System

- Transition Guidebook (English)
- Transition Guidebook (Spanish)



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Contact Us



401-270-0101

Monday through Friday 8:00 AM - 5:00 PM



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Website: ripin.org

Facebook: @RIPIN.ORG

Twitter/Instagram: @RIPIN_RI











	Thursday, 6/29/2023 7:30am – 8:30am EST
Topic:	Guardianship
Presenter:	Jeannine Casselman, MLPB







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