

Roadmap College

Webinar #2
Identifying Resources and Making Them Available
Thursday, June 9
3pm – 4pm ET



Welcome

Abby Zier Alyesh





Housekeeping















Kids deserve the best.











A part of the Chicagoland Children's Health Alliance











Our goal, simply put

"Ask how the child and family are doing. Every visit. Every time"





A Roadmap for Supporting Emotional Health for Roadmap Children with Chronic Conditions and their Families: A Plan to Accompany the Readiness Checklist

STEP 1

STEP 4

Self-assess your readiness using the Readiness Checklist

STEP 2

Collect simple baseline data:

Was there documentation that patient and family emotional health was assessed during this visit?

STEP 3

Set an aim



Con

TRY CHANGES, MEASURE IMPROVEMENT

Conduct PDSA cycles. Begin with Key Driver 1 and progress through Key Drivers 2, 3, and 4, focusing your tests of change on improvements related to your readiness self-assessment. Use the "potential change strategies" in the driver diagram to gather ideas to try. Start small; for example, one patient, one clinic day, one inpatient rounds. Revise as you learn and improve.

Key Driver #1: Develop Awareness

Use the potential change strategies to increase your awareness of the challenges and stresses of living with/parenting a child with a chronic condition.

Key Driver #2: Identify resources; make them available

Use the Developing a
Resource List tool to create
or update a list of resources
specific to your practice's
location and patient
population. Ensure you
have a crisis plan for mental
health emergencies for
patients and for families.

Key Driver #3: Develop knowledge, know-how and confidence

Review Roadmap videos and conversation guides to develop or hone your approach to initiating conversations about emotional health.

Key Driver #4: Build assessment and surveillance into your clinic flow

Begin assessing emotional health at the time of diagnosis and continue through each clinical encounter.



Continue to test and measure ways to embed discussions about emotional health into your daily care. Collect additional measure data and repeat the Roadmap Readiness Checklist. Expand your successful PDSA cycles, and implement successful changes. Ensure that your measure data support the effectiveness of the changes as you move to implementation.





Objectives

Understand

Understand the current state of your practice setting having an up-to-date list of resources to support the emotional health of children with chronic conditions and their families.

Use

Use change strategies to make resources available to patients and their families.

Understand

Understand ways to connect patients with peers for additional support.



Agenda

10 min	Welcome & Current State	Abby Zier Alyesh
10 min	Raise Awareness Recap	Abby Zier Alyesh Carole Lannon
5 min	Overview of Identifying Resources & Making Them Available	Carole Lannon
30 min	Identifying Resources and Making Them Available Connect Patients & Families with Peer Support Q&A Develop a List of Resources Q&A Application	Stacey Lihn Jill Plevinsky
5 min	Next Steps	Abby Zier Alyesh



May reporting

Barriers

Successes

- How to bring up emotional health
- Documentation

- Remembering to Document conversations
- Minimizing time as a barrier
- Social worker available every week for families



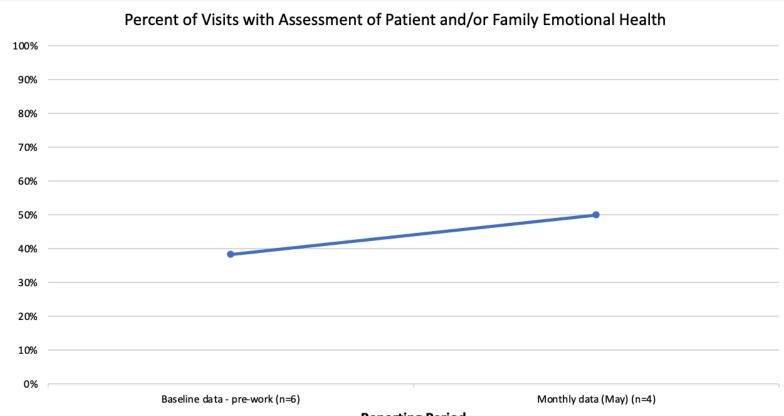
May reporting

May range: 10%-90%

1. Visits with emotional health assessment

Data as of 5.31.22

Percent of total visits with a response of documented discussion or used a screening tool.



N=# of sites
Four sites reviewed
~10 charts each

Reporting Period

Per the Roadmap College Data Use Agreement, do not copy, forward or otherwise share this data beyond members of your hospital's Roadmap team



Raise Awareness Recap Abby Zier Alyesh Carole Lannon



Feedback

• Refreshed my team goal of making sure emotional health is a part of our approach

100% of participants heard at least one idea from webinar #1 that they will be taking with them.

Takeaway tests

- What step can you take to overcome one (or more) of your barriers to raising awareness among your colleagues and staff?
- How can you raise awareness with one of the audiences you identified as needing to be aware of the impact emotional health has on patients and families?

Overview: Identifying Resources and Making Them Available Carole Lannon





Supporting Emotional Health for Children and Adolescents with Chronic Conditions and Their Families

Potential Change Strategies

Global Aim

Patients and their families living with chronic pediatric conditions receive proactive support to promote emotional health, including assessment and care for emotional health, as a routine part of care for chronic conditions.

Specific Aim (example)

By December 1, 2022, ___ practice will improve ___% from baseline the number of visits in which children with chronic conditions and their families' emotional needs are assessed.

Population

Patients and families living with pediatric chronic conditions.

Key Drivers

1. Develop awareness

2. Identify resources; make them available

3. Develop knowledge, know-how, and confidence

4. Build surveillance and assessment into routine visit workflows

- Review patient and family stories that acknowledge the stresses of living with/parenting a child with a chronic condition
 - Video: How are you <u>Doing?*</u>
 - Manuscript: A Roadmap to Emotional Health for Children and Families with Chronic Pediatric Conditions*
- Increase awareness of the <u>particular emotional</u> health stresses for racial and ethnic minorities
 - Video: The Impact of Being Black While Living with a Chronic Condition*
- Develop a list of resources of emotional health support services; keep it updated
 - o Tool: Developing a Resource List*
- Develop a crisis plan for mental health emergencies for patients and families
- Integrate psychosocial professionals (when available)
- Refer patients and families to peer support groups and peer mentoring programs
- Offer resources regardless of whether they have been identified as at-risk
- Introduce resources at multiple time points; patients/families may not be ready at first
- Complete the ABP Continuing Certification Part 2 activity: Emotional Health and Resilience for Patients and Families with Chronic Pediatric Conditions
- Learn and practice the Normalize, Ask, <u>Pause</u> technique for starting discussions about emotional health
 - Video: How to Feel Comfortable Starting Discussions about Emotional Health*
- Use guides: Talking about Emotional Health: Example Conversations*
- View Roadmap videos: Talking about Emotional Health*
- Include emotional health as a review of systems item during pre-visit planning and team rounds
- Introduce assessment of emotional health to patients and families at the time of diagnosis so it becomes part of expected visit routine
- Provide opportunities for patients / families to express emotional health needs:
 - o "What Matters Most" or "What do you want to talk about today?" cards
 - o Space on intake form



^{*}These resources are available on The Roadmap Project's website

Specific Aim

By December 1, 2022, ____ practice will improve ____% from baseline the number of visits in which children with chronic conditions and their families' emotional needs are assessed.

2. Identify resources; make them available

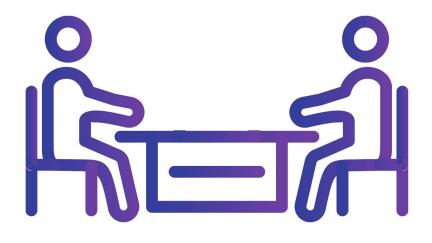
- Develop a list of resources of emotional health support services;
 keep it updated
 - Tool: Developing a Resource List*
- Develop a crisis plan for mental health emergencies for patients and families (*more to come...*)
- Integrate psychosocial professionals (when available)
- Refer patients and families to peer support groups and peer mentoring programs
- Offer resources regardless of whether they have been identified as at-risk
- Introduce resources at multiple time points; patients/families may not be ready at first

Focus today

Having a community is important

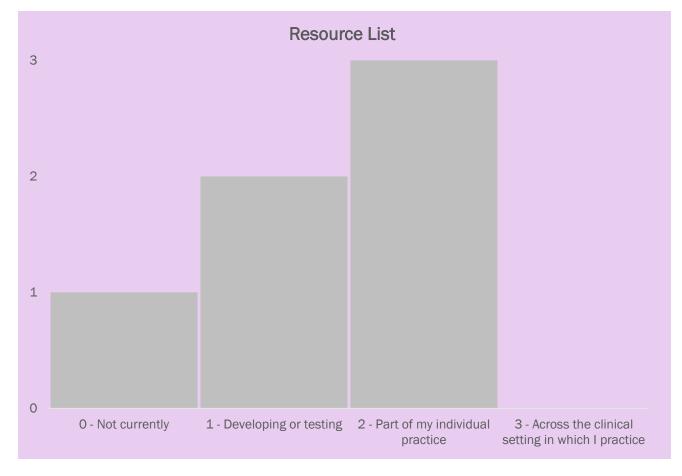
Have a therapist when you need one





Self-Assessed Readiness (April 2022)

- B. Our practice setting has an up-to-date list of resources available to support the emotional health of children with chronic conditions and their families that includes:
- mental health providers (e.g., social workers, psychologists, psychiatrists, other licensed providers) in the health system and/or community, when available
- local or national peer-to-peer support resources for patients
- local or national peer-to-peer support resources for families (e.g., parents and/or siblings)







Developing a Resource List For Providers and Clinical Teams

Following are several resource documents that have been developed in collaboration with patients, parents, and clinicians as part of The Roadmap Project, which aims to improve the emotional health of children and adolescents with chronic conditions and their families. These resources and the template may also be helpful for children, adolescents, and families without the experience of chronic conditions.

- Overview: Developing a resource list: An introductory page that outlines what
 questions a clinical team will want to consider when developing a resource list
 and what to share with patients.
- 2. Example resources for clinical centers to consider: Clinicians and clinical teams highlighted the need to develop a resource list for their practice setting for those families who wanted referrals for resources outside of the health system.
- Resource list template: A template that can be adapted by local centers to give
 to patients and families about "how to find a therapist". This template can be
 adapted as appropriate by the center, perhaps including identified local or state
 resources.



Connect Patients & Families with Peer Support Stacey Lihn





Stacey Lihn

- Mother to an 12-year-old daughter with Hypoplastic Left Heart Syndrome
- Founder and President of Sisters by Heart
- Executive Leadership Team member, NPC-QIC and FON

The power of community to create health is far greater than any physician, clinic, or hospital.

~ Dr. Mark Hyman



Peer-to-Peer Support



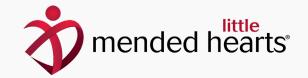
NATIONAL & LOCAL ENGAGMENT

- Evolution of peer-to-peer support
- Benefits to patient/family communities
- Having resources/links readily available to share with families











Resources: Peer-to-Peer Support

- Sisters by Heart https://www.sistersbyheart.org
- Linking Hearts
 https://sistersbyheart.wearecnxion.com/
- Linked by Heart https://www.sistersbyheart.org/linked-by-heart
- FON SV Chats <u>http://events.r20.constantcontact.com/register/event?llr=kdgqiilab&oeidk=a07ej4gxqv23a8370</u> bd
- Conquering CHD <u>https://www.conqueringchd.org/involvement/connect-with-others</u>
- Mended Little Hearts
 https://mendedhearts.org/connect/chapters_groups/
- Adult Congenital Heart Association <u>https://www.achaheart.org/your-heart/programs/heart-to-heart/</u>
- Transplant Families -<u>https://www.transplantfamilies.org/resources</u>



"I participated in the event last evening and as a parent of an older Fontan recipient I want to offer encouragement to all of the parents. You are doing the right thing to stay involved and learn as much as possible. You are the key to your child's success and know more about your child's sensitivities and feelings. It is up to you to have the knowledge base to be your child's intermediary in difficult situations. Don't be afraid to speak up and ask questions."

-Parent of an older Fontan patient



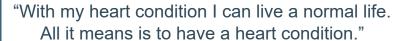
Meg Didier
Co-Founder of SVCC



Amanda Harper Co-Founder of SVCC

Single Ventricle Chat Quotes

May 2022 92 participants from 6 countries



-Young Fontan patient

"This is the first time I'm meeting someone like me!"

-13-year-old Fontan patient



Stacey Lihn, Mom to Zoe Co-Founder of SVCC

"My husband and I were in your breakout group at the FON chat last night. I just have to tell you how wonderful and necessary it is to have a community like this. Thank you so very much to everyone at FON and for all of your great work at Sisters by Heart.

Alicia, seemingly, hit the nail on the head when she explained what is was like during the early teen years, trying to grasp the idea of a possibly uncertain future. My son (13 years old, HLHS) is going through that now."

-Parent of a younger Fontan patient





Ladder of Engagement

A framework for helping centers to:

- Assess current level of engagement
- Identify barriers to increased engagement
- Set goals that enhance engagement

Levels of Engagement

No plans to engage patients/parents Plans to engage patients/parents Have some patients/parents involved regularly Have a network of patients/parents actively involved

Levels

Potential Causes

Actions You Can Take

No plans to engage patients/parents

- Don't know where to start
- Insufficient staff time
- Lack of leadership buy in/alignment

Plans to engage patients/parents

- · Lack of relationships with patients and families
- Traditional boundaries between patients and clinicians
- Inability to support families with time, money, and resources to participate
- Patients and families lack awareness of FON

Have some patients/parents involved regularly

- Have "go to" patients/parents but relationships aren't widespread
- Patient and families cannot decipher medical jargon or lack understanding of complex medical systems
- Language barriers exist for some patients
- Patient/families may not be able to commit sufficient time

Have a network of patients/parents actively involved

- Have reliable families to tap into who are active/creative in finding solutions
- Hospital supports and resources are being utilized
- Patients and families possess a passion to help move goals/projects forward

- · Acknowledge that you don't have engagement at your center
- Identify value-add for leadership
- Identify a champion (clinical or volunteer) to spearhead effort
- Talk to FON staff or other care centers who have done this well
- Begin to identify action items you can take and build a plan
- Create a list of patients at your center with single ventricle
- Reach out to 2 or 3 patients you have a connection with
- Identify financial or other resources to support family's participation (e.g., bus passes, parking, technology)
- Share FON One-Pager with patients at every visit
- Create a social media account/page to connect with patients, spread awareness, and share resources
- Share Single Ventricle Connection Chats
- Host a watch party for FON's SV Patient Day
- Develop QR codes to easily share resources with patients
- Target 2 3 additional patients or parents to engage
- · Provide resources in layman's terms
- Utilize volunteers to help educate families on medical system
- Utilize an interpreter to communicate as needed
- Develop flyers/pamphlets in multiple languages
- Identify "menu" of options with a range of time commitments
- Invite patients to participate in QI work and research
- Create a self-sustainable patient and family led council
- Utilize current patients/families to engage new ones
- Host an annual meet and greet with patients and families
- Provide resources for patients to advocate for themselves





Engagement Challenge!



- Challenge #1: Take one action from the ladder of engagement.
- Challenge #2: Have one patient or family team member as part of your Roadmap College, NPC-QIC and/or FON team!





Q&A





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Develop a List of Resources Jill Plevinsky





Jill Plevinsky

- Pediatric Psychologist at Children's Hospital of Philadelphia
- Founder, Patient Advisory Committee,
 ImproveCareNow network (inflammatory bowel disease (IBD)



DEVELOPING A GUIDE TO FINDING RESOURCES

National vs. local

• National resources might include SAMHSA's National Helpline, NAMI, MentalHealth.gov, or the National Suicide Prevention Lifeline

• Local resources might include specific referrals, or information for how to find a therapist with private vs. public health benefits in the states you serve



DIGITAL MENTAL HEALTH & APPS

- 3-step framework for recommending mHealth apps for pediatric populations
 - 1. Narrow the target problem, the intended recipient of the intervention, and the range of treatment options
 - 2. Explore the scientific evidence supporting the app, privacy policies, and user experience
 - 3. Contextualize use your clinical expertise/stakeholder feedback to determine whether the app is a good fit

The Needle in the Haystack: Identifying Credible Mobile Health Apps for Pediatric Populations during a Pandemic and beyond @

Alexandra M Psihogios, PhD ™, Colleen Stiles-Shields, PhD, Martha Neary, MSc

Journal of Pediatric Psychology, Volume 45, Issue 10, November-December 2020, Pages 1106–1113, https://doi.org/10.1093/jpepsy/jsaa094

Published: 17 October 2020 Article history ▼



SAMPLE DOT PHRASE

Finding A Therapist/Psychologist

With Private Insurance

viet or neverbalagiet in vour area. Dalour are como urave other familiae have found useful There are many ways to find

With Medicaid Insurance

1) Visit your insurance's web

2) Call your insurance - You services." By calling that nun

3) Visit www.psychologytoda the screen. Choose from the

- Insurance
- Issues: look through the | 2)
 Treatment Orientation: st
- 4) Ask your pediatrician Ma 3)

When searching for a therap

- Are you taking new patients
- · Do you accept my insuranc
- Do you have experience us 4)
 Do you have experience trε 4)

It is recommended to try at le

plan details, zip code and dif 1) Locate the **number on the back of your ID card**. There may be a separate phone number for "mental health."

Or you can call your **local county mental health office**: The easiest way to find the appropriate number would be to google "[COUNTY NAME] Behavioral Health" or "[COUNTY NAME] Mental Health".

For NJ residents, you can visit NJ Performcare website at: https://www.performcarenj.org/ and click "search for a provider" or call 1-877-652-7624 and follow the instructions listed below.

Provide **basic information** over the phone: Name of caller and patient; Insurance; Location; "Looking for child/adolescent therapy services"

Initial screen on phone or in person (process varies)

- a. In the assessment, be sure to (A) be specific about emotional health and related symptoms (ex. depression, anxiety) and (B) describe the impact of these symptoms on the child's life (ex: school, concentration, sleep)
- b. Request Cognitive Behavioral Therapy (CBT)

It is recommended to try at least 3 visits before deciding that it is not a good fit and searching for a different provider. Speak to your therapist or front desk staff at the clinic if you feel you would benefit from a different therapist.

If you have trouble finding at In the case of an emergency or for concerns related to safety, dial 911 or take yourself and/or your child to the Emergency Department.

24/7 National Suicide Prevention Lifeline: 1-800-273-TALK (8255) En Español: 1-888-628-9454 24/7 Crisis Text Line: Text "HOMF" to 741-741



WHERE TO BEGIN?

- Brainstorm ideas, identify already existing resources you may not need to re-invent the wheel!
- Organize your guide to resources by audience (e.g., age group, severity of concerns).
- Include your patient/parent partners in developing your materials ask about usability (e.g., how do families want to access this information?).
- Consider how you might keep your resource list updated if needed.
- Test it out (PDSA!).



Q&A



Cardiac Specific Resources

- Ollie Hinkle Heart Foundation https://www.theohhf.org/
- Lucile Packard Children's Hospital Stanford- CHD Care Compass -https://chdcarecompass.com/

Discussion and Application



Discussion

1. If you currently have a resource list...

- What tips do you have for others who are just getting started?
- What ideas do you have to ensure your resources are current?

2. If you are just getting started...

- What questions do you have for Jill and your peers?
- Where will you begin?



Next Steps Abby Zier Alyesh



Before Webinar #3

Takeaway tests:

- <u>Establish</u> or <u>update</u> your practice setting's list of resources to support the emotional health of children with chronic conditions and their families that includes:
 - mental health providers (e.g., social workers, psychologists, psychiatrists, other licensed providers) in the health system and/or community, when available
 - local or national peer-to-peer support resources for patients
 - local or national peer-to-peer support resources for families (e.g., parents and/or siblings)
- If needed, understand options for referring parents
 - to mental health providers
 - if in crisis

Tasks:

- Visit the Roadmap College participant page to see pre-reading
- Report Month 2 data on REDCap by June 24





