



Roadmap College

Webinar #2

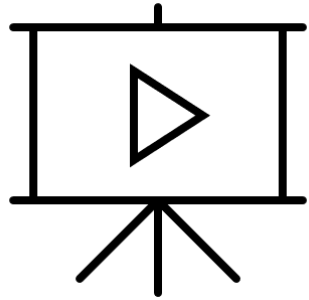
Identifying Resources and Making Them Available

Thursday, June 9

3pm - 4pm ET

Welcome

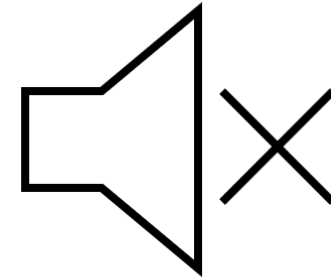
Abby Zier Alyesh



Webinar is
being recorded



Recording &
slides will be
posted



Mute mic

Housekeeping





Our goal,
simply put

*“Ask how the child
and family are doing.
Every visit. Every
time”*



SETUP

STEP 1

Self-assess your readiness using the Readiness Checklist

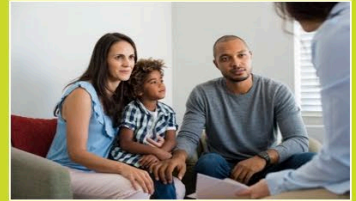
STEP 2

Collect simple baseline data:

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

STEP 3

Set an aim



STEP 4

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.

TRY CHANGES, MEASURE IMPROVEMENT

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.

STEP 5

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 <i>Application</i> | Stacey Lihn Jill Plevinsky |
| 5 min | Next Steps | Abby Zier Alyesh |

May reporting

Barriers

- How to bring up emotional health
- Documentation

Successes

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

May reporting

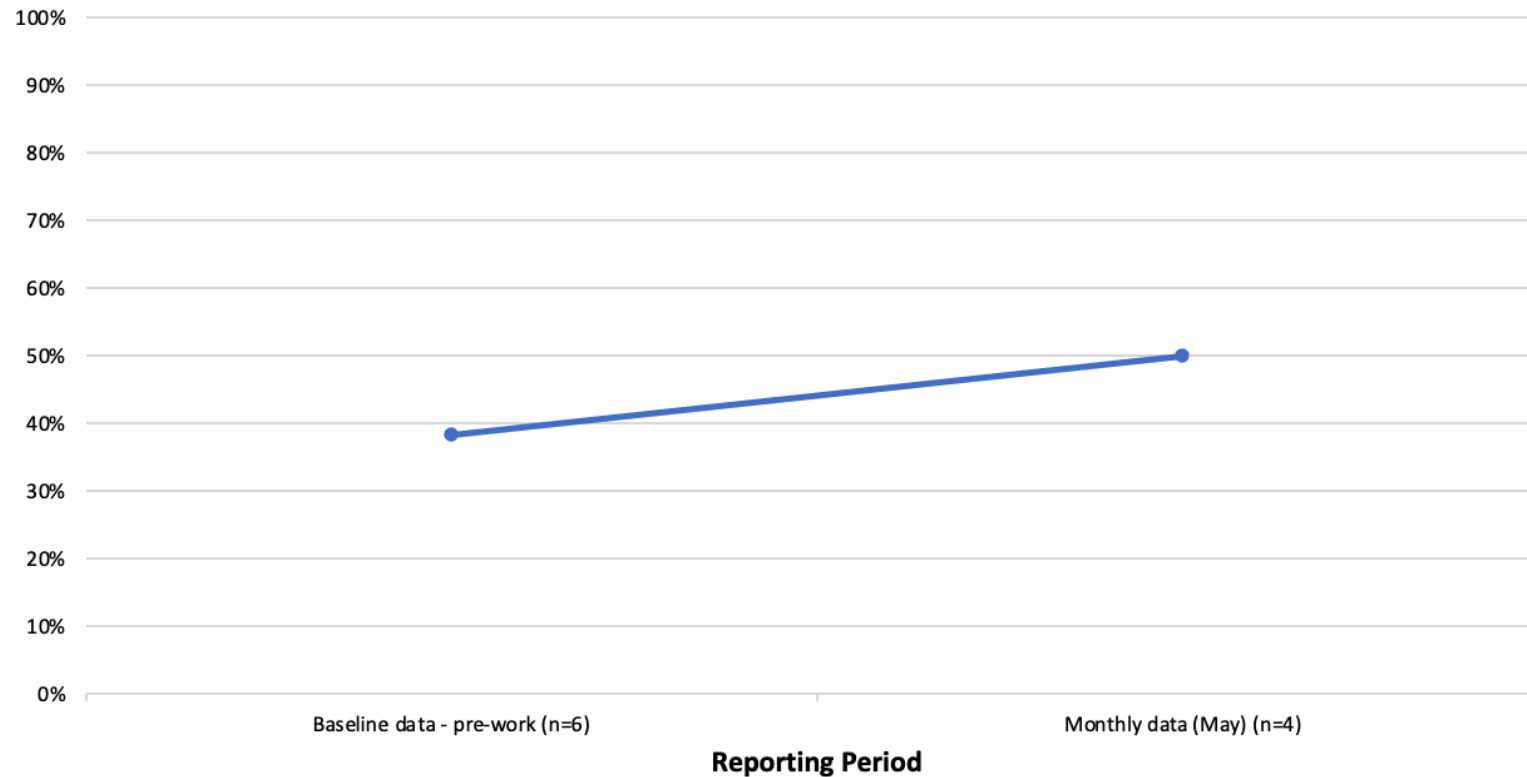
May range: 10%-90%

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.

Percent of Visits with Assessment of Patient and/or Family Emotional Health



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

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

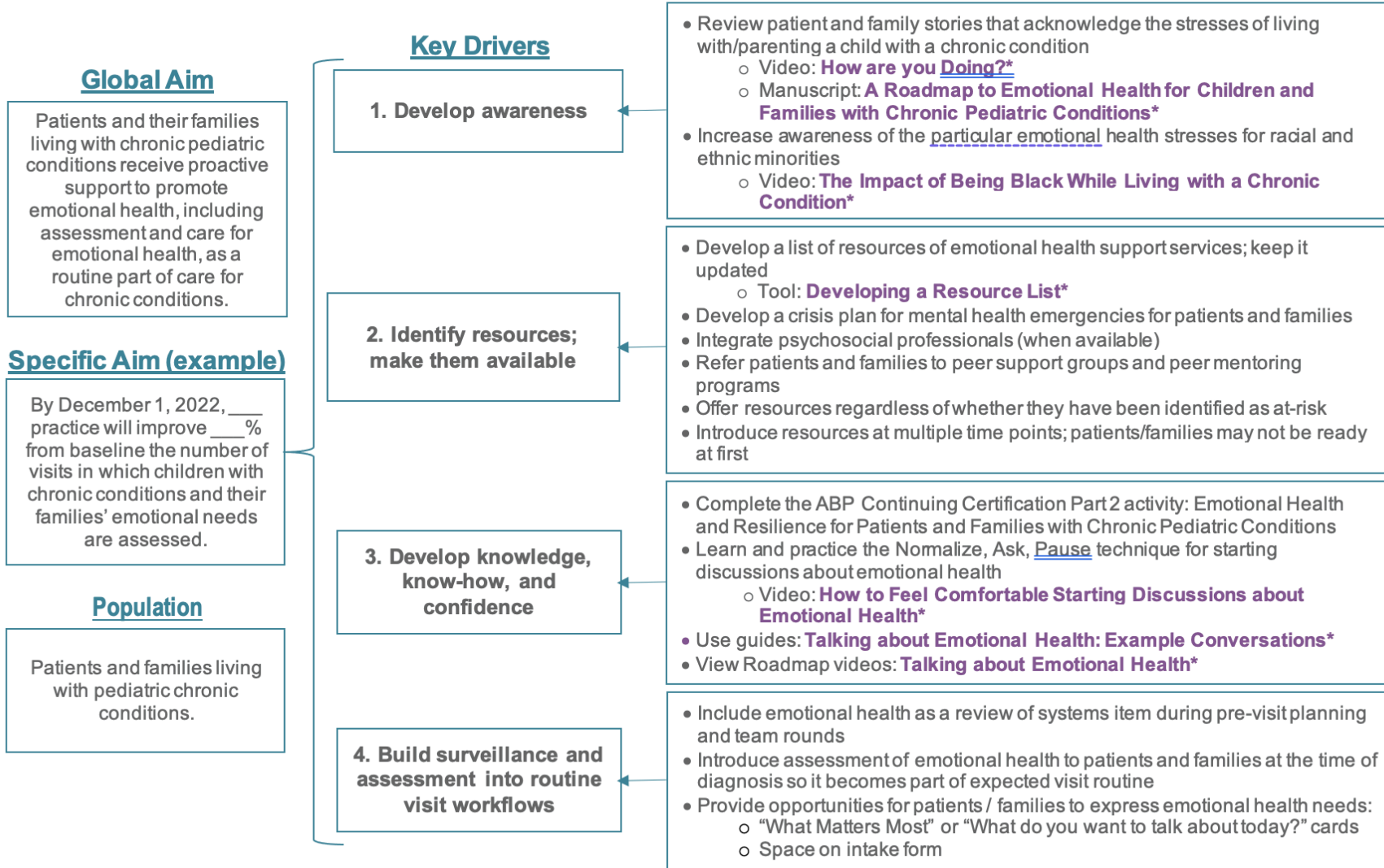
- What step can you take to overcome one (or more) of your barriers to raising awareness among your colleagues and staff?
- How can you raise awareness with one of the audiences you identified as needing to be aware of the impact emotional health has on patients and families?

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



*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.

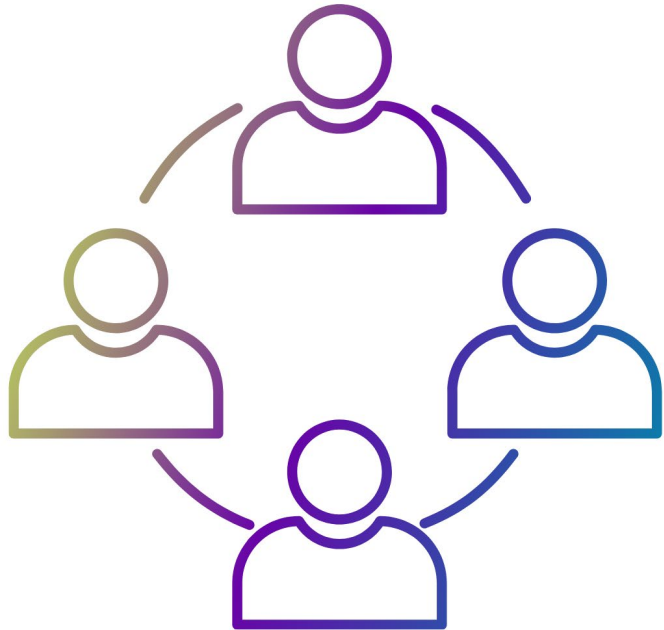
2. Identify resources; make them available

- 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

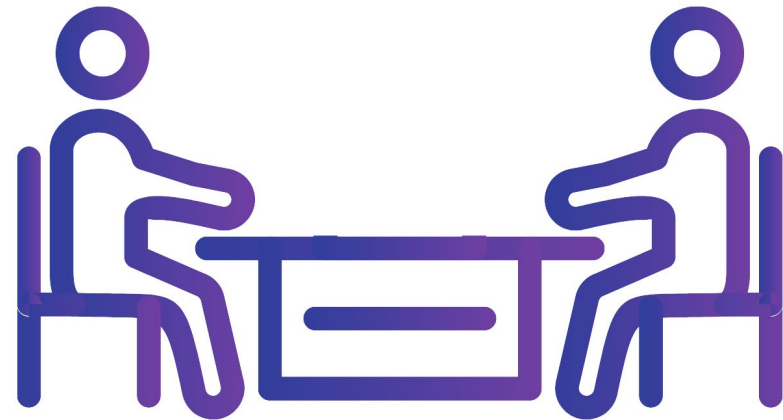


Focus today

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.

1. **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.
3. **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 ENGAGEMENT

- 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
<http://events.r20.constantcontact.com/register/event?llr=kdgqiilab&oeidk=a07ej4gxqv23a8370bd>
- Conquering CHD
<https://www.conqueringchd.org/involvement/connect-with-others>
- Mended Little Hearts
https://mendedhearts.org/connect/chapters_groups/
- Adult Congenital Heart Association
<https://www.achaheart.org/your-heart/programs/heart-to-heart/>
- Transplant Families -
<https://www.transplantfamilies.org/resources>

Single Ventricle Chat Quotes

May 2022
92 participants from 6 countries



Stacey Lihn, Mom to Zoe
Co-Founder of SVCC

“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

“With my heart condition I can live a normal life.
All it means is to have a heart condition.”

-Young Fontan patient

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

-13-year-old Fontan patient

“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 it 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

1



No plans to engage patients/parents

2



Plans to engage patients/parents

3



Have some patients/parents involved regularly

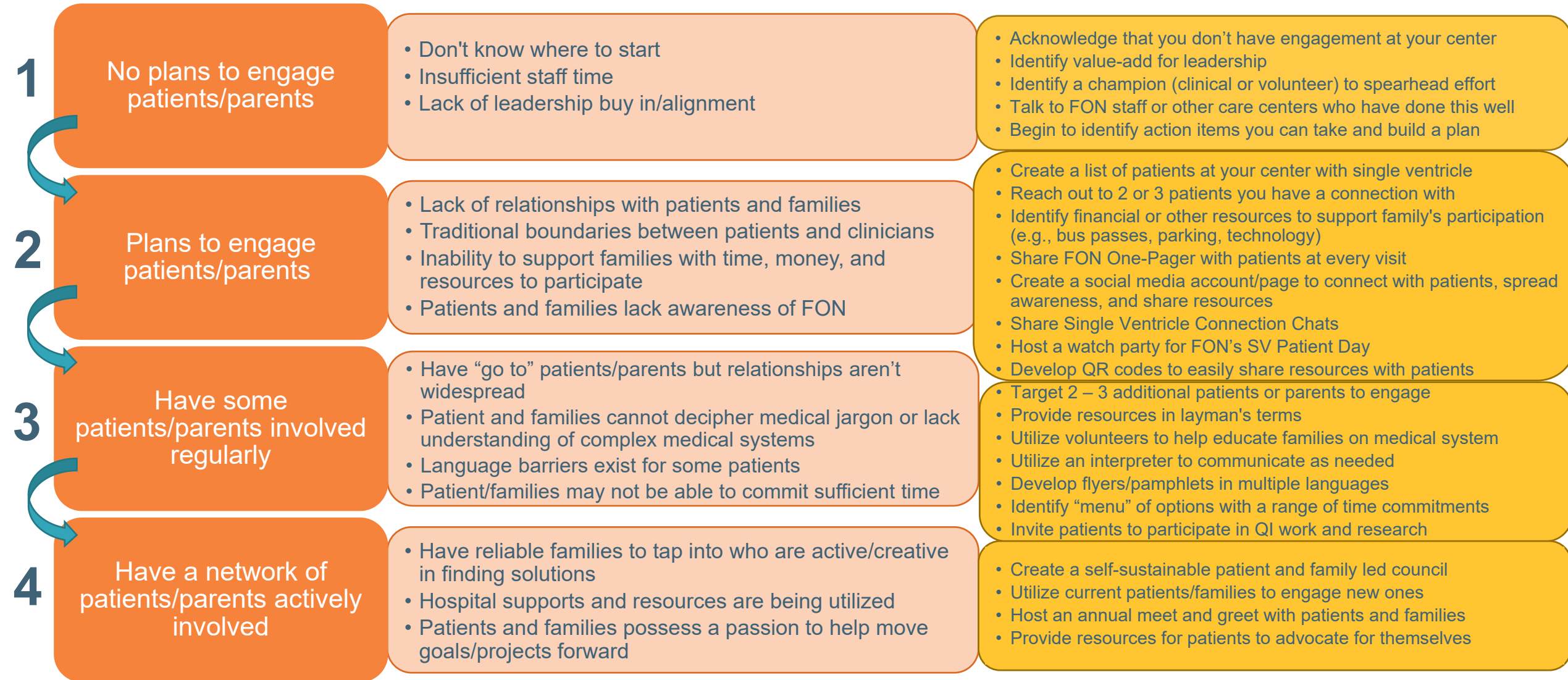
4

Have a network of patients/parents actively involved

Levels

Potential Causes

Actions You Can Take





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

Developing a Resource List For Providers and Clinical Teams

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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 FREE

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

There are many ways to find a therapist or psychologist in your area. Below are some ways other families have found useful.

1) Visit your insurance's web plan details, zip code and dif

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

3) Visit www.psychologytoday.com the screen. Choose from the

- Insurance
- Issues: look through the l
- Treatment Orientation: st

4) Ask your pediatrician - Ma

When searching for a therap

- Are you taking new patients?
- Do you accept my insuranc
- Do you have experience us
- Do you have experience tre

It is recommended to try at le

If you have trouble finding a

With Medicaid Insurance

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.

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

3) **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)**

4) 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.

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 "HOME" 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:

- Establish or update 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



Evaluation

