



Improving the Emotional Health of Children with Chronic Conditions: *The Roadmap Initiative*

Carole Lannon MD MPH

Professor of Pediatrics, Cincinnati Children's
Senior Quality Advisor, American Board of Pediatrics

Marion Burton Invitational Lecture
South Carolina chapter of the American
Academy of Pediatrics

*“Pediatricians have to be in the
forefront to make sure that kids get
what they need”.*
(Dr. Marion Burton)

National Focus on Pediatric Mental Health



The National Academies of
SCIENCES • ENGINEERING • MEDICINE

CONSENSUS STUDY REPORT



**Fostering Healthy
Mental, Emotional, and
Behavioral Development
in Children and Youth**



A NATIONAL
AGENDA



2019 National Academy of Medicine

- Specifically calls out emotional health in children with chronic illness.
- *...these findings reinforce the relationships between physical and mental health, as well as the key role of family functioning.*

For those with a chronic condition:

Increased rates of mental health diagnoses (especially anxiety & depression) with 2.4 x increased costs

Emotional health is tied to health outcomes



65% of pediatricians, including subspecialists, surveyed by the American Academy of Pediatrics indicated that they lacked training in recognizing and treating mental health problems.

*Partnering with
Patients and
Families to
Advance Quality
September 2016*



American
Board of
Pediatrics



My son Jake has critical congenital heart disease.

In 23 years of complex care at a top-notch hospital, I do not ever remember a doctor asking Jake or myself how we were coping emotionally. But there were many times when my husband and I, and Jake, were not coping well.

And although Jake has half a heart, the mental health struggles have been the more painful part of our journey in many ways.

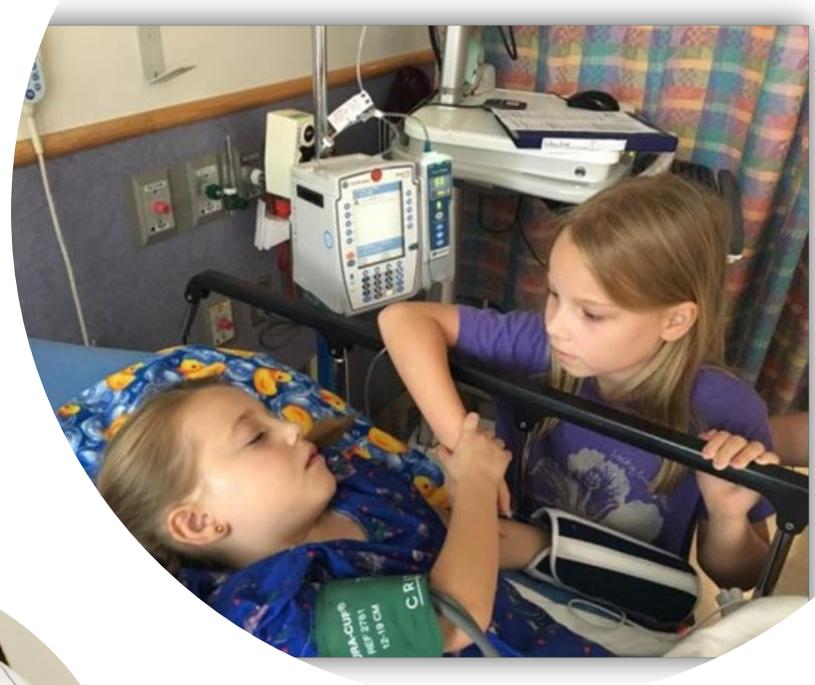
-Diane Pickles

Pediatrics. 2020; A Roadmap to Emotional Health for Children and Families with Chronic Pediatric Conditions



Living with a chronic pediatric condition:

- Is challenging
- Can cause stress and altered coping
- Has potential lasting mental health impacts
- Impacts mental, physical and emotional health of family members





The Roadmap Project

*Improving the Resilience and Emotional Health of
Children with Chronic Conditions and Their Families*



The
Roadmap
Project

THE AMERICAN BOARD *of* PEDIATRICS
FOUNDATION



The *Aim* of the Roadmap Initiative

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

“How Are You Doing?”



“I haven’t really asked patients or families about emotional health. How do I start?”



“Our center is going to start annual anxiety and depression screening for teens. How should we explain this to patients and families?”

What we have learned

You don't have to be a mental health professional to make a difference.

Patients and parents don't expect clinicians to be perfect.



THE ROADMAP PROJECT



RAISE AWARENESS

about the emotional
impact of living with
a chronic condition.



IDENTIFY RESOURCES

and make them
available (e.g. peer-
to-peer, therapeutic
support, and patient
and family crisis
plans).

DEVELOP SKILLS

and confidence to
address emotional
health.



BUILD SURVEILLANCE

and assessment into
routine clinical
processes.

LEARN MORE AT WWW.ROADMAPFOREMOTIONALHEALTH.ORG

Example Roadmap Resources

- Developing a Resource List and Choosing a Therapist
- Summary of Billing Strategies
- A Patient Shares How Clinicians Can Empower Patients by Asking About Emotional Health
- Example Conversations (one-pagers and videos)
- Maintenance of Certification Part 2 and 4 activities
- Readiness checklist for clinicians and practices

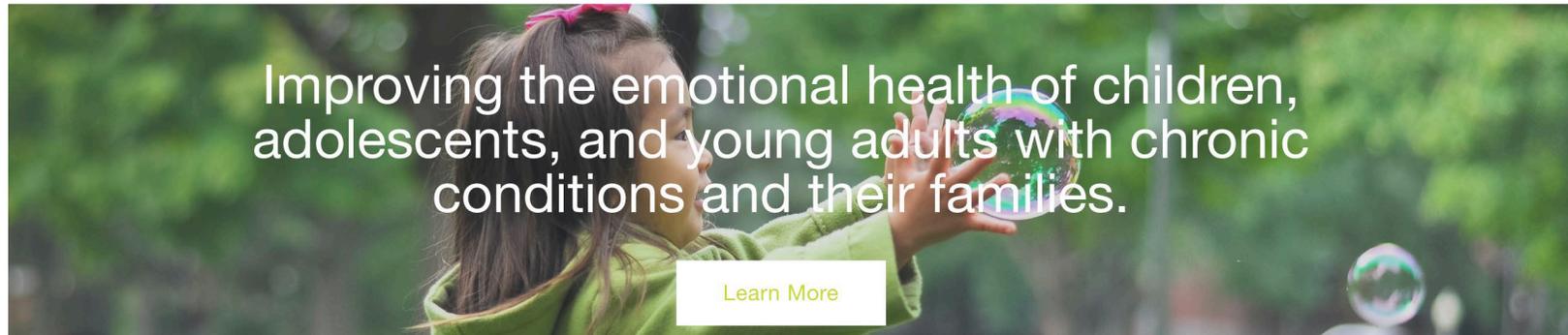


Roadmap Tools and Resources



The
Roadmap
Project

[About](#) [Tools & Resources](#) [News & Events](#) [Patients & Families](#) [Roadmap Initiatives](#) [Contact Us](#)
[Videos](#)



<https://www.roadmapforemotionalhealth.org>



The
Roadmap
Project

THE AMERICAN BOARD *of* PEDIATRICS
FOUNDATION



A few Roadmap themes to highlight

- Addressing Stigma
- Beginning Conversations About Emotional Health
- Understanding the Impact of Being Black on Living with a Chronic Condition



Addressing Stigma: Conversations with Youth

Johanna Bergan

Stockman lecture

AAP NCE 2022



Youth

Motivating

Others through

Voices of

Experience

National

www.youthmovenational.org

**YOUTH
MOVE
NATIONAL™**



The
Roadmap
Project

THE AMERICAN BOARD of PEDIATRICS
FOUNDATION



After sifting through thousands of insights, the most frequently repeated form of help was to have

“adult helpers (teachers/doctors/other professionals) having the language to talk respectfully about mental health and then be able to offer to help.”



“It is more than okay to talk about mental health with your young patients. In fact, it is exactly what they want and need.”





“When YOU (as the provider) are the one to start the conversation and bring up questions around mental health, anxiety, depression – this normalizes talking about mental health. This is such important modeling from a caring adult”.

Starting Discussions About Emotional Health



Starting the Conversation

NORMALIZE + ASK + PAUSE

- ✓ Communicate that emotional difficulties are common and expected in this situation
- ✓ Set up the discussion so that the easy answer is to acknowledge emotional difficulties
- ✓ Minimize the likelihood of “I’m fine”



Starting the Conversation

NORMALIZE + ASK + PAUSE

- ✓ Open-ended
- ✓ Avoid checklist-like questions
- ✓ Less is more
- ✓ Pay attention to your non-verbal communication

Starting the Conversation

NORMALIZE + ASK + PAUSE

- ✓ Communicates that you want to hear the answer
- ✓ Gives the patient/parent time to gather their thoughts and decide whether to share
- ✓ This may be the first time they've been asked
- ✓ Try again next time even if they don't share



The Impact of Being Black on Living with a Chronic Condition



The Background Trauma of Lived Experience



For me, it has been difficult to respond in the hospital when someone asks, “how are you doing?” ... I need to be in a safe space to feel secure enough to be vulnerable.

It's the trauma of having a medically fragile child, it's the trauma of just being a Black individual in the world today. We carry around trauma. I don't think people are aware that past and current events play a part.

As an example, I got pulled over by the police during the holidays in a suburban town. I changed the radio station from hip hop and turned on the Christmas music right away. I've got my daughter's art stickers on the back of the car, and a car seat in the back. But none of that mattered--**all I thought about was Sandra Bland and what happened during her traffic stop.**



Playing the Game by Code-Switching

My husband and I were always cognizant of what we wore when going to the hospital. He would change into business casual so he wouldn't be thought of as "a thug". My husband noted that when he presented his insurance card with the name of his corporate employer, the perception of who we were changed. When I was there alone, there was often an assumption that I was a single mom with no insurance.

We tried to build rapport with each doctor and nurse.... we were concerned parents, we understand what's going on, we have questions, so that they would **to treat us the same as if we were White.**

I had to make them accept us. I'm trying to talk a certain way, dress a certain way, be a certain way so that staff find us acceptable and feel comfortable talking with us. It is exhausting trying to deal with bias on top of worrying about your son's health and care. It was hard to let my guard down. I always knew that I had to be strong.





The Child Protective Services Concern

You learn that you have to be seen as non-threatening, well-educated, and strong in order for healthcare professionals to deem you acceptable.

One triplet had several medications, a G-tube, oxygen, and a heart monitor. I wanted to be sure that the hospital team knew I could handle taking him home. I made sure that I always presented myself with the attitude “I have this” because some fear was always in the back of my mind about Child Protective Services.

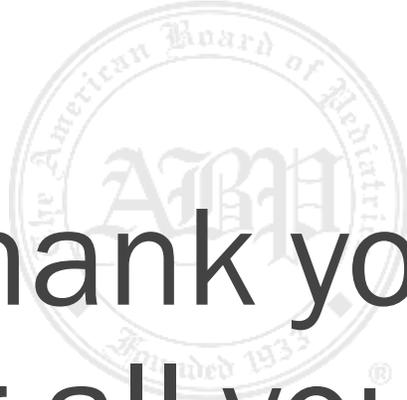
As a Family Advisor in the NICU, I would coach Black families about talking with the care team., so they would not be seen as emotional or angry. I would tell Black parents, “I want you to be able to come see your kid. You don’t want them to say you can’t come back up here. Your baby needs you.”





Thank you.





Thank you.

Thank you for all you do every day
to help children and families.



The Roadmap Project



<https://www.roadmapforemotionalhealth.org>