



The  
Roadmap  
Project

## A CHANGE PACKAGE

Supporting the Emotional Health of  
Children and Adolescents with  
Chronic Conditions and Their  
Families



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**Patients and families with chronic conditions cite emotional health as one of their top concerns. The Roadmap Project began with a request from three parents of children with chronic conditions to the American Board of Pediatrics:**  
*"Please create a roadmap to improve the emotional health of our children."*

For children and adolescents, the stress of living with a chronic condition can lead to anxiety disorders,<sup>1</sup> exacerbations in their conditions,<sup>2,3</sup> challenges in self-care and treatment adherence,<sup>2,3</sup> and delays in reaching developmental milestones.<sup>4</sup> Further, these effects can persist long term, with associations between childhood chronic physical illness and adult depression and anxiety.<sup>5</sup>

Chronic conditions in children can also have substantial negative impact on the physical and emotional health of family members, including parents<sup>6,7</sup> and siblings.<sup>8</sup> Parent psychological distress is a risk factor for poorer outcomes in youth with a variety of chronic medical conditions, and parents have significant potential to positively or negatively impact their child's adjustment to chronic illness.<sup>9</sup> Siblings of children with chronic conditions may experience psychological, academic, and peer-related difficulties at school.<sup>10</sup>

While there have been numerous successful efforts to improve the physical care of pediatric patients living with chronic conditions, there has not been the same focus on enhancing emotional health. Despite evidence that emotional health impacts health outcomes, current pediatric trainees do not report high levels of competence in the assessment and treatment of children with emotional health concerns.<sup>11</sup> In a 2020 survey completed by 4,121 subspecialty pediatric fellows, 56.4% of pediatricians surveyed reported they were interested in addressing the emotional health concerns of children with chronic conditions. However, only 20.5% reported they had the competence to treat children and adolescents with emotional health concerns.<sup>12</sup>



*"My son Jake has critical congenital heart disease. In 23 years of complex care at a top-notch hospital, I don't 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 parts of our journey in many ways. It's not enough that Jake has survived ... he needs to thrive."*

-Diane Pickles, parent

**The Roadmap Project** was established by the American Board of Pediatrics Foundation with support to The James M. Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital; additional support has been provided by the David R. Clare and Margaret C. Clare Foundation. The aim of the Roadmap Project is that patients with chronic conditions and their families receive proactive support from clinical teams to foster emotional health.<sup>13</sup> Our tools and resources exist to support clinicians in building the awareness, understanding, and confidence to acknowledge and address patient and family emotional health needs.



## How was this Change Package Developed?

The strategies described here are informed by expert opinion and experience of patients, parents, and clinicians, including psychologists. Many, but not all, have been tested in a group of clinical practices. This document should be seen as a beginning 'toolkit' providing strategies and ideas for those looking to start working in this area. We expect that it will be a living document, expanding and improving as new resources and strategies are added.

## Who is this Change Package for?

The target audience for this Change Package is clinical teams working to improve care for patients and families living with chronic pediatric conditions, including clinicians, improvement specialists, social workers, psychologists, patients, and parents. This is typically subspecialty pediatricians and trainees, although general pediatricians will find the resources and change ideas useful. Providing excellent and equitable emotional and mental health support requires multi-disciplinary collaboration. Pediatricians and pediatric specialists participating on these teams may not provide the primary therapeutic strategies but must be knowledgeable and supportive of interdisciplinary efforts.<sup>14</sup>



"As a clinician in a subspecialty, it is often easier to focus on 'your disease,' but failure to acknowledge the emotional toll of chronic disease on patients and families undermines the achievable and ideal treatment success. I did not think I had time to incorporate another 'screening' into my clinic visits, but I learned it does not have to be perfect – it just needs to be authentic.

Normalize the emotional stress, ask how they are feeling, pause to allow an answer, and then keep asking every visit. Listening is an intervention itself, so just start asking. It may be one of the most important elements of care you provide to your patients."

***Aliese Sarkissian, MD***

*University of North Carolina at Chapel Hill*

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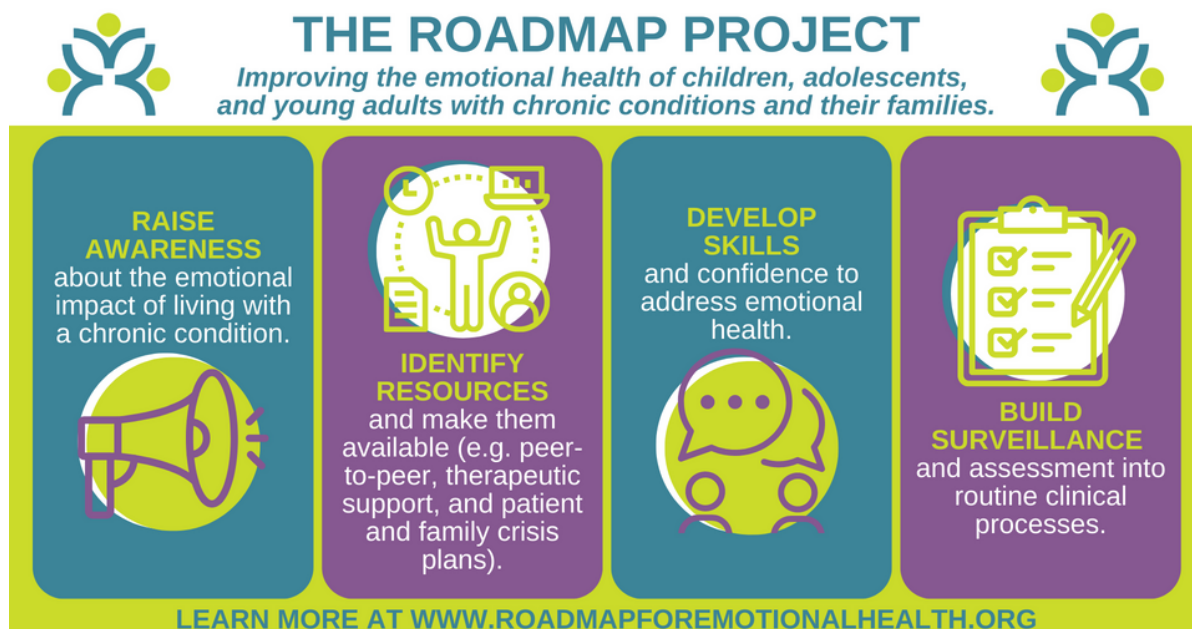
"When YOU, as the provider, are the one to start the conversation and bring up questions around mental health, anxiety, depression – this normalizes talking about mental health. This is such important modeling from a caring adult."

***Johanna Bergan,***

*patient voice and former Executive Director of Youth MOVE National*

## What is the Work Ahead?

Embedding ongoing assessment of emotional health needs into each clinical encounter will require that individual practices intentionally embed process and system changes. A Comprehensive Plan to Guide Your Efforts is summarized on the following page and described in detail throughout the remainder of this document. The changes you and your team make will fall within four categories, which we call “key drivers” of improvement. You will self-assess to know where to get started, and then progress sequentially through the key drivers based on the context of your team and institution.



The Roadmap Project is supported by the American Board of Pediatrics Foundation and the David R. Clare and Margaret C. Clare Foundation.

**1. Develop awareness and understanding of the significant impact of emotional health on patient and family functioning:** Clinicians and their support staff must first understand that emotional health is important and tightly connected to physical health. They have a unique role to play in the validation and assessment of the emotional health needs of patients with chronic conditions.

**2. Identify support resources and make them available:** Patients will often need help connecting to numerous kinds of resources, which range from peer communities that can help patients feel supported and less isolated to therapists when they need professional help to strategies for self-care.

**3. Develop knowledge, know-how, and confidence in discussing emotional health:** Patients want their subspecialty clinicians to feel comfortable assessing and addressing emotional health concerns because they develop long-term relationships with their subspecialty providers. While patients don't expect subspecialty providers to be perfect in how they inquire about emotional health, being able to initiate discussions about emotional health is an important skill.

**4. Build surveillance and assessment of emotional health into routine visit workflows:** Practice settings that are effectively assessing patients and family members for emotional health needs start early, ask often, and build these approaches into their systems, from clinic workflows to billing strategies.

**Your work will need to encompass all four of these key drivers to successfully assess and address the emotional health needs of all patients and their families in your practice and, ultimately, across the clinical setting in which you practice. You might already do some of the changes suggested below, in which case you will be able to progress to others. The key drivers describe the ‘what’ that must be in place across practice settings that are effectively assessing emotional health needs of their patients. This Change Package depicts some of the ‘how’ to get there.**





## A Plan to Guide Your Efforts

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<b>STEP 01</b>	<b>Self-assess your readiness using the Readiness Checklist</b>
<b>STEP 02</b>	<b>Collect simple baseline data: Was there documentation that patient and family emotional health was assessed during this visit?</b>
<b>STEP 03</b>	<b>Set an aim</b>
<b>STEP 04</b>	<b>Conduct PDSA Cycles</b>
<b>STEP 05</b>	<b>Continue to Test and Measure</b>



## Step 1: Self-Assess Your Readiness Using the Readiness Checklist

**Rationale:** The Roadmap Project has identified several activities or “pre-cursor tasks” for clinical teams and their practice settings to effectively have conversations to assess and support emotional health for patients and families with chronic pediatric conditions. This Checklist tool is designed to help a practice setting assess readiness for including emotional health as a routine part of excellent care.

**Suggested frequency:** Complete the assessment at three points in time: (1) before beginning work (baseline), (2) at the midpoint in time based on your stated aim (to be completed in Step 3), and (3) on the stated date of your aim.

**Instructions:** Complete the checklist as an individual. If you are working with a team, then come together as a team to discuss your self-assessments. Ultimately, agree on one score per team.

**Interpretation:** Scores are not meant to be tallied. Rather, they are intended to suggest opportunities for improvement. Items self-assessed as a 0 (not currently) and 1 (developing or testing) are indicators that teams will want to consider improvement changes related to these topics. With active efforts to make improvements, sites should expect to see progress towards self-assessing as a 2 (part of my individual practice) and 3 (across the clinical setting in which I practice). The Readiness Checklist components (a-f) align with the Roadmap Key Driver Diagram.



[\*\*CLICK HERE TO COMPLETE THE READINESS CHECKLIST\*\*](#)

## Step 2: Collect Simple Baseline Data

**Measure:** Percent of visits with assessment of patient and/or family emotional health

**Rationale:** Improvement in the percentage of visits in which children with chronic conditions and their families' emotional needs are assessed is the primary outcome of interest.

**Suggested frequency:** At baseline and monthly thereafter.

**Instructions:** Sample 10 charts each month of patients seen by providers participating in improvement efforts. We recommend 10 charts per month, although even a handful will help your improvement efforts. For each chart, assess the following:

**Was the emotional health of the patient and/or family assessed during this visit? Select all that apply:**

☐

**Not assessed**

☐

**Documented discussion** with patient and/or family to verbally assess emotional health and quality of life (e.g., mental health and psychological wellbeing, physical activity, sleep, family life, quality of life, coping, social support, school or work functioning, pleasurable activities/interests/hobbies)

☐

**Used screening tool** (e.g., PROMIS®, anxiety, depression, QOL, etc.)

If you responded yes to #3 (used screening tool), was there documentation that the results of the screening were discussed with patient and/or family?

☐

**Yes**

☐

**No**

**Interpretation:** Calculate the percent of visits each month in which patient and/or family emotional health is assessed. Numerator: total number of charts with 2 (documented discussion) or 3 (used screening tool) scored. Denominator: Total number of charts assessed.

### Step 3: Set an Aim

**Template:**

**Instructions:** Complete the blanks to set your aim.

By [insert date], \_\_\_\_\_ practice will improve \_\_\_\_\_% (baseline) to \_\_\_\_\_% the number of visits in which children with chronic conditions and their families' emotional needs are assessed.



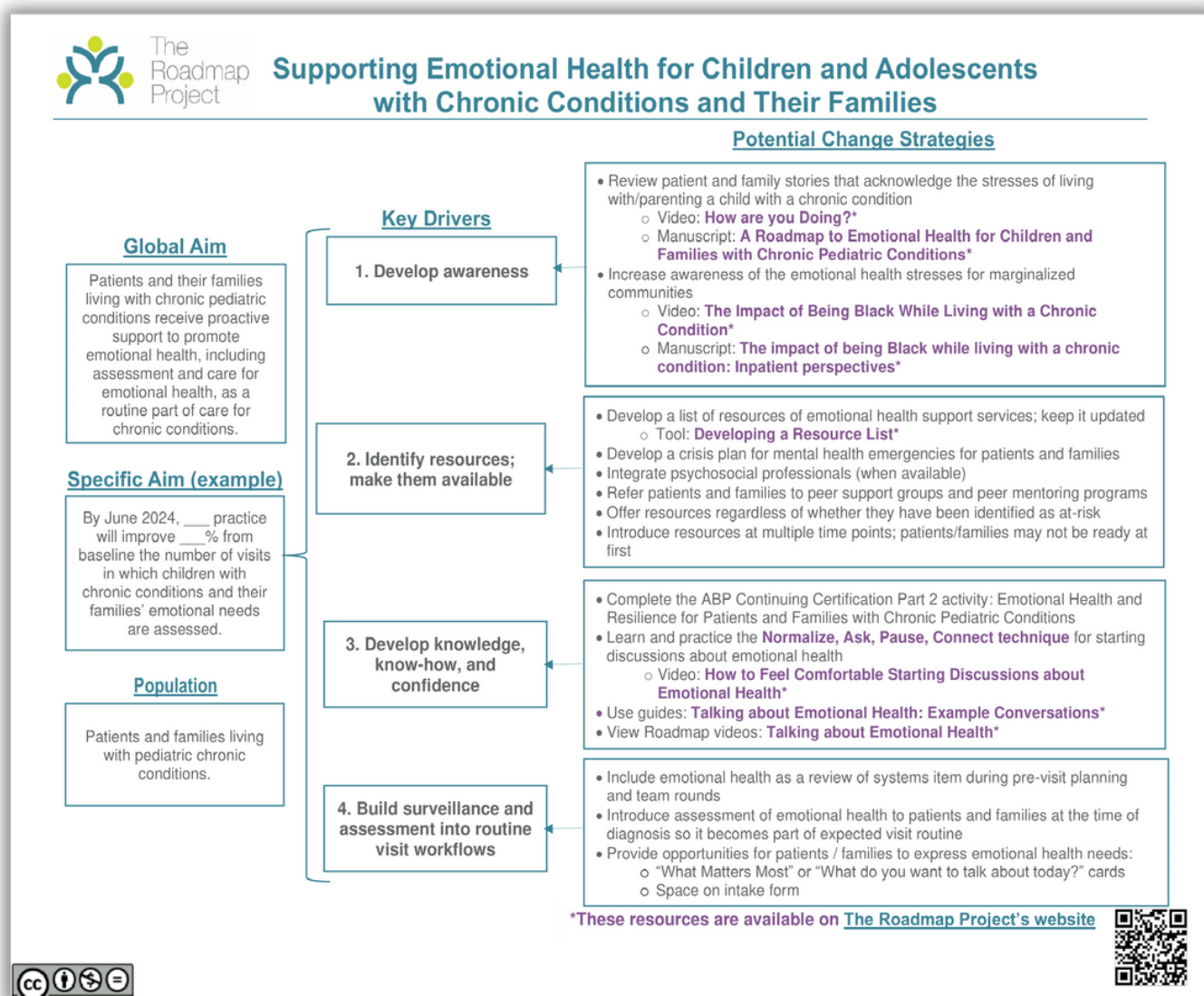
## Step 4: Conduct PDSA Cycles

### A Key Driver Diagram to Guide Your Efforts

A key driver diagram for improvement efforts in this area is included on the next page. While individual clinicians will likely identify additional drivers and changes that could lead to improvement in their specific environments, this is intended to help clinical teams get started thinking about choosing changes to test that are most likely to lead to improvement.

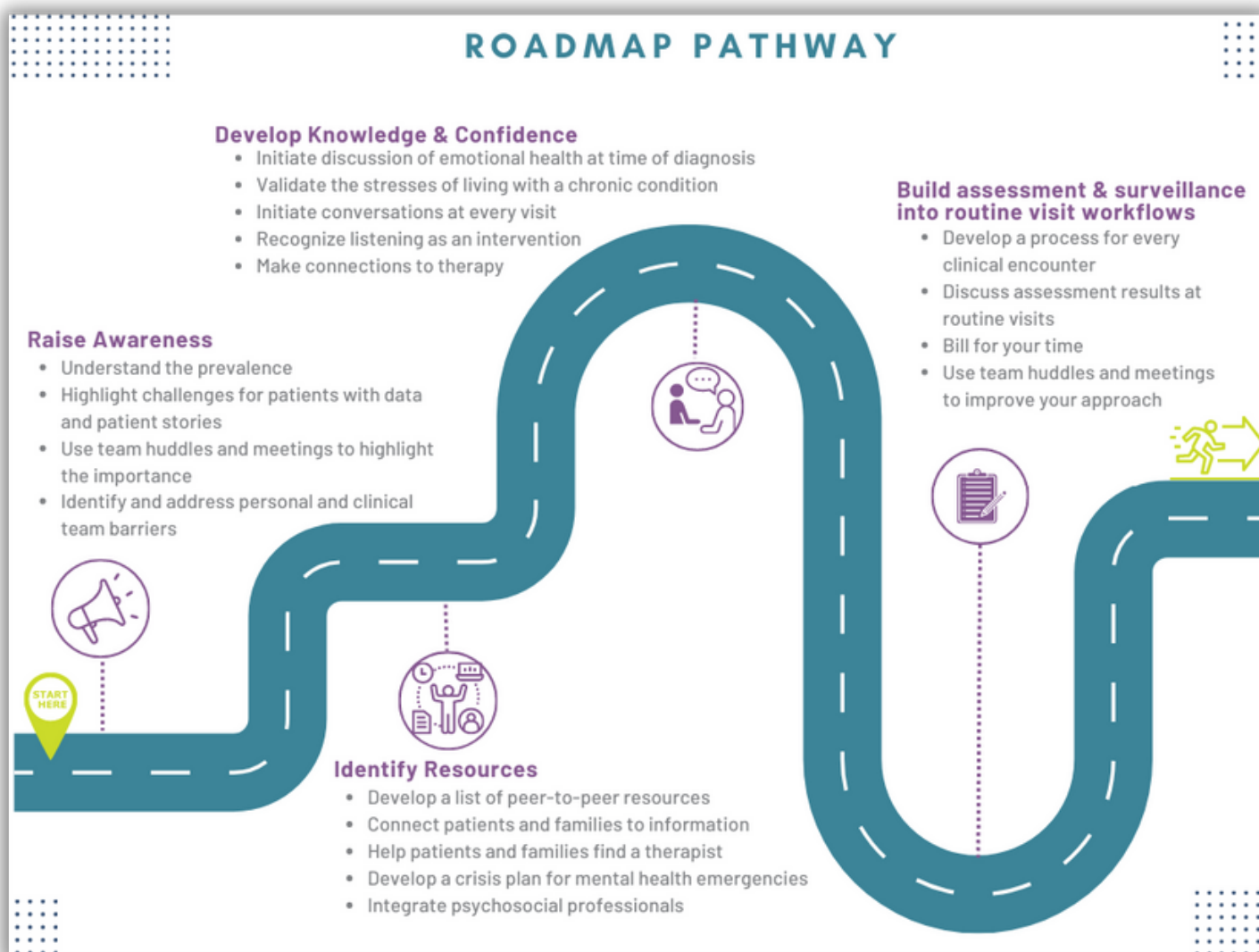
Following the driver diagram is a range of specific possible changes to optimize emotional health for pediatric patients and families living with a chronic condition. This list was developed based on review of literature and other evidence, and with ideas and input from chronic condition-focused Learning Networks, and parent and patient partners.

The changes are organized according to the key drivers included in the key driver diagram to help individuals and improvement teams decide what to try based on the area of focus they would like to address. There is sequencing built into the key drivers, but you should also factor in how you self-assessed in each of the driver areas to determine where you want to get started. Many of the changes will need to be customized to meet the needs of specific populations of patients and families.



## Step 5: Continue to Test and Measure

Continue to test and measure ways to embed discussions about emotional and equitable 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 supports the effectiveness of the changes as you move to implementation.



## Key Driver 1: Develop Awareness

Clinician awareness of the impact of a chronic pediatric condition on emotional wellbeing; the need for improved emotional health support including surveillance, screening, treatment, and follow-up; and the potential mitigating role of resilience.

Use the potential change ideas to increase your awareness of the challenges and stresses of living with/parenting a child with a chronic condition. Additionally, consider who among your staff needs an awareness of the challenges and stresses of living with/parenting a child with a chronic condition. There is general evidence regarding the prevalence of emotional health concerns with chronic disease.<sup>15, 16</sup> If possible, identifying disease- or specialty-specific data to share with a clinical team is helpful.

Potential Change Ideas	Resources
<p><b>Understand the prevalence of emotional health challenges in your subspecialty area.</b></p> <ul style="list-style-type: none"><li>Review the literature about emotional health impact of chronic conditions on your patient population.</li><li>Gather data from your practice or health system about your practice population, e.g., some centers routinely collect screening data.</li></ul> <p><b>Use data along with patient and family stories to highlight the challenges of living with a chronic condition for staff and colleagues in your practice setting.</b></p> <ul style="list-style-type: none"><li>Embrace the iterative nature of raising awareness. Expect conversations to be ongoing. Return to individuals and meetings to check in, share information, and share learning.</li></ul> <p><b>Use team huddles, regular clinic meetings to share the importance of addressing the emotional health of those living with chronic conditions.</b></p> <ul style="list-style-type: none"><li>Determine your target audience(s) (e.g., clinic pod, division, trainees, faculty, etc.). Think about your practice setting. Who needs to be aware, from the front desk to final point of contact?</li></ul> <p>Key message:</p> <ul style="list-style-type: none"><li>This is important.</li><li>You might feel like you don't have time or that you don't know how to do this.</li></ul> <p>We will learn together and build the skills.</p> <p><b>Identify and address any personal or clinical team barriers to providing emotional health in your clinical setting.</b></p> <ul style="list-style-type: none"><li>Use Roadmap resources to raise your own awareness and your colleagues'.</li><li>Set aside time with each audience to discuss barriers and solutions.</li><li>A good starting place is one-on-one conversations with your colleagues. You do not need to know all the answers yourself. You can seek them together.</li><li>Over time, consider division meetings, grand rounds, and other communication channels in your system.</li></ul>	<ul style="list-style-type: none"><li><a href="#">A Patient Shares How Clinicians Can Empower Patients by Asking About Emotional Health</a> (video)</li><li><a href="#">Addressing Emotional Health: A Self-Assessment (Answer Key)</a></li><li>American Board of Pediatrics Maintenance of Certification Part 2 Activity (<a href="#">Login to your ABP Portfolio to Begin</a>)</li><li><a href="#">How are you doing?</a> (video)</li><li><a href="#">The Impact of Being Black While Living with a Chronic Condition</a> (video)</li><li><a href="#">A Roadmap to Emotional Health for Children and Families with Chronic Pediatric Conditions</a></li><li><a href="#">Psychological Aspects of Living with A Chronic Condition: Information for Patients and Families</a></li></ul> <div><p>"Structural racism compounds the challenges of chronic illness and calls attention to recognized areas of concern for Black patients and parents during hospitalization: 1) the impact of trauma associated with racially motivated current events on the hospital stay; 2) the need for "code-switching" (adjusting one's style of speech, appearance, behavior, and expression to optimize the comfort of others) when interacting with hospital providers; and 3) the concern of Black parents about the potential threat of Child Protective Services being called by hospital teams."</p><p><b><u><a href="#">The impact of being Black while living with a chronic condition: Inpatient perspectives</a></u></b> (<i>Journal of Hospital Medicine</i>)</p></div>



## Key Driver 2: Identify Resources, Make Them Available

Providing a list of resource options for patients and families can be helpful in identifying a therapist when one is needed. 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.

Potential Change Ideas	Resources
<p><b>Think of peer-to-peer support as part of the treatment plan.</b></p> <ul style="list-style-type: none"><li>Refer patients and families to peer support groups and peer mentoring programs, both locally and nationally.</li></ul> <p><b>Develop a list of resources of emotional health support services.</b></p> <ul style="list-style-type: none"><li>Ask around for existing resources – you may not need to reinvent the wheel! The Roadmap Project offers this <a href="#">Developing a Resource List</a> overview and template to guide you.</li><li>Organize your resource guide by audience.</li><li>Include patient/parent partners in developing materials.</li><li>Determine how you can keep your list updated.</li><li>Test it out! And ask patients/and families if they were successful in using the resource.</li></ul> <p><b>Connect patients and families to information about emotional health.</b></p> <ul style="list-style-type: none"><li>Offer resources regardless of whether patients and families have been identified as at-risk.</li><li>National resources will provide general information.</li><li>Local resources can include support services and names of therapists.</li><li>Introduce resources at multiple time points; patients/families may not be ready at first.</li></ul> <p><b>Be able to help patients and families find a therapist when they need one.</b></p> <ul style="list-style-type: none"><li><a href="#">Share resources that describe how to find a therapist.</a></li></ul> <p><b>Develop a crisis plan for mental health emergencies for patients and for families.</b></p> <ul style="list-style-type: none"><li>Remember to develop a crisis plan for family members who may not be able to receive services at pediatric facilities.</li></ul> <p><b>Integrate psychosocial professionals (when available)</b></p>	<p><b>For clinicians:</b></p> <ul style="list-style-type: none"><li><a href="#">Developing a Resource List</a></li><li>Webpage: <a href="#">Roadmap Patient and Family Webpage</a></li></ul> <p>.....</p> <div><p>“Please let your patients and families know that caring for a child with chronic illness is often a difficult journey. Please tell your patients and families ‘it is okay to admit you need help.’” <b>Robyn Kinebrew, M.A.,</b> <i>mother of twins with sickle cell disease</i></p></div> <p>.....</p> <div><p>“More focus needs to be on proactive mental and emotional support for improving outcomes. There is a difference between living and existing. We need more tools in the toolbox as patients.”</p></div>





## Key Driver 2: Identify Resources, Make Them Available (continued)

Patients and families should have access to peer-to-peer support as a resource to make connections. Having a community that can validate, normalize, and support patients and families with chronic conditions holds great value.

Potential Change Ideas	Resources
<p><b>Practice self-care</b></p> <ul style="list-style-type: none"><li>Self-care looks different for everyone, but some common ideas include mindfulness, meditation, sleep, exercise, schedule a positive activity. Apps for mindfulness recommended by psychologist advisors to Roadmap include: MindShift, Smiling Mind, Mango Health, and Mindful Powers.</li></ul> <p><b>Connect with peers for support</b></p> <ul style="list-style-type: none"><li>Your clinicians might have information about local and national peer support groups for your condition.</li></ul>	<p><b>For Patients and Families:</b> Find a therapist or mental health professional</p> <ul style="list-style-type: none"><li><u><a href="#">Considerations for Choosing a Community-Based Therapist</a></u></li><li>If in crisis, call 988.</li></ul>



“People gravitate toward peer support because of its humanizing effect on our challenging health care system. And we love that it provides that personal connection to better understand physical and emotional impacts of chronic illness and it is 100% patient-centered . . . Peer-to-peer supports looks different for everyone, but that feeling of validation and understanding by someone who has walked in your shoes – we learn from each other and gain tools to live healthier lives as parents, patients, and siblings.”  
**Stacey Lihn, parent of child with single ventricle heart disease and president, Sisters-by Heart**



## Key Driver 3: Develop Knowledge, Know-How, and Confidence

Clinician knowledge, know-how, and confidence to make discussions about emotional health part of their clinical relationship with patients.

Potential Change Ideas	Resources
<p><b>Begin initiating discussions about emotional health at the time of diagnosis.</b></p> <ul style="list-style-type: none"> <li>If a relationship is already established, describe this as a practice change.</li> <li>If applicable, consider pre-natal support for parents.</li> <li>Use Roadmap resources to become comfortable having conversations about emotional health with patients and families.</li> </ul> <p><b>Validate the stresses about living with a chronic condition.</b></p> <ul style="list-style-type: none"> <li>Share with patients and families that <u><b>it is common to feel stress and worry in their circumstances.</b></u></li> </ul> <p><b>Initiate conversations about emotional health at every encounter (clinic or bedside)</b></p> <ul style="list-style-type: none"> <li>Consider using the <u><b>“Normalize-Ask-Pause-Connect” technique</b></u> to start conversations (see video).</li> </ul> <p>Continue to check in over time:</p> <ul style="list-style-type: none"> <li>Follow up to demonstrate your investment.</li> <li>If parents don't take clinicians up on therapy connections initially, suggest other forms of self-care and continue to check in with them.</li> <li>Be familiar with a few things patients can do while they deal with waitlists – for example, breathing app, gratitude app, positive event every week.</li> </ul> <p><b>Recognize that listening is an intervention in itself.</b></p> <ul style="list-style-type: none"> <li>Listening will not solve problems, but it signals important support to patients and families.</li> <li>Create effective communication channels by asking “How are you doing”? Patients want to hear this from their sub-specialty provider.</li> </ul> <p><b>Make connections to therapy, when appropriate</b></p> <ul style="list-style-type: none"> <li>Validate that it is common to seek support through the help of a therapist in these circumstances.</li> <li>Share the connection between emotional and physical health and how support from a therapist may be helpful.</li> <li>Explain the process for finding a therapist. If a referral is internal, use names and communicate confidence and familiarity.</li> </ul>	<ul style="list-style-type: none"> <li>Use guides: Talking about Emotional Health: <u><b>Example Conversations</b></u></li> <li>Video: <u><b>How to Feel Comfortable Starting Discussions about Emotional Health</b></u></li> <li>Read Erica Sood, PhD's <u><b>Normalize-Ask-Pause-Connect Approach</b></u></li> </ul>

### NORMALIZE-ASK-PAUSE-CONNECT

#### NORMALIZE

- Communicate that emotional difficulties are common and expected.
- Set up the discussion to promote emotional disclosure.
- Minimize the likelihood of “I’m fine.”

- “I know from working with other teens that it’s common to feel down or depressed when [illness-specific stressor].”
- “I hear from a lot of parents that they grieve the loss of [pre-illness experience].”
- “I always ask about [emotion] because how you are emotionally is just as important as how you are physically.”

#### ASK

- Use open-ended questions.
- Keep your questions brief.
- Pay attention to your non-verbal communication.

- “How about you/your family?”
- “How has your family been affected?”
- “What has [illness-specific stressor] been like for you?”

#### PAUSE

Communicate non-verbally that you want to hear the answer.

Give the patient/family time to gather their thoughts and decide whether to share.

#### CONNECT

- Use reflection to communicate that the patient/family was heard and understood.
- Validate feelings.
- Connect to additional providers and resources when available.

- “Thank you for sharing. It sounds like this has been a really hard time. I appreciate learning more about how you are doing so that we can continue to support you/your family.”
- “I can understand why you might feel this way.”
- “Our team has a [resource/person] that may be able to provide additional support around [challenge/concern]. Is it okay if I connect you?”

# Key Driver 4: Build Assessment and Surveillance into Your Clinic Workflow

Routine emotional health surveillance and assessment are part of the clinic and family structure/workflow. Begin assessing emotional health at the time of diagnosis and continue through each clinical encounter.

Potential Change Ideas	Resources
<p><b>Develop a process with your clinical team to ensure that emotional health is part of every clinical encounter.</b></p> <ul style="list-style-type: none"><li>• Begin by planning small tests of change.</li><li>• Use huddles to review strategies for individual patients and their caregivers.</li><li>• Determine discipline specific roles for starting the conversation with or without screening tools, sharing resources, and referral to resources when needed.</li><li>• Develop documentation norms in order to follow patient and family emotional needs.</li><li>• Communicate all changes and welcome feedback to improve processes.</li></ul> <p><b>Establish real-time feedback and discussion of emotional health assessment results into routine visits.</b></p> <ul style="list-style-type: none"><li>• Holistically address both emotional and physical health needs.</li><li>• When needed, refer to therapeutic support.</li><li>• If a screening tool is used, provide feedback about results to the patient and/or family.</li></ul> <p><b>Bill for your time discussing and following up on emotional health.</b></p> <ul style="list-style-type: none"><li>• Use <a href="#"><u>Billing Strategies to Support Effective Emotional Health as a resource.</u></a></li></ul> <p><b>Use meetings to discuss addressing emotional health as routine care.</b></p> <ul style="list-style-type: none"><li>• Highlight successful process testing with tips and tools for spread to other providers, disciplines, and healthcare teams.</li><li>• Review strategies for assessing and addressing emotional health during huddles and division meetings.</li><li>• Create dedicated time in team huddles for emotional health discussions related to both process testing and feedback for specific scenarios.</li></ul>	<ul style="list-style-type: none"><li>• <a href="#"><u>Billing Strategies to Support Effective Emotional Health</u></a></li></ul> <div><p>“I’ve learned that it takes little time to validate the stress that families undergo ... I have the confidence to do that now. And I’ve learned I don’t have to have all the answers in one visit!”</p><p><b>Corey Stiver, MD, Cardiologist</b></p></div> <div><p>“The goal is the medical provider is driving the discussion about emotional health... 90% of the time listening will be the intervention.”</p><p><b>Mary Pat Gallagher, MD</b></p></div> <div></div>

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# References

1. Cobham VE, Hickling A, Kimball H, Thomas HJ, Scott JG, Middeldorp CM. Systemic Review: Anxiety in Children and Adolescents With Chronic Medical Conditions. *Journal of the American Academy of Child Adolescent Psychiatry*. 2020 May; 59(5):595-618
2. Davis AM, Graham TB, Zhu Y, McPheeters ML. Depression and medication nonadherence in childhood-onset systemic lupus erythematosus. *Lupus*. 2018 Aug;27(9):1532-1541.
3. Hommel KA, Denson LA, Crandall WV, Mackner LM. Behavioral Functioning and Treatment Adherence in Pediatric Inflammatory Bowel Disease: Review and Recommendations for Practice. *Gastroenterology & Hepatology*. 2008 Nov 1;4(11):785
4. Barlow JH, Ellard DR. The psychosocial well-being of children with chronic disease, their parents and siblings: an overview of the research evidence base. *Child Care Health Dev*. 2006 Jan;32(1):19–31
5. Small M, Piercy J, Pike J, Cerulli A. Incremental burden of disease in patients diagnosed with pulmonary arterial hypertension receiving monotherapy and combination vasodilator therapy. *Advances in Therapy*. 2014 Feb;31(2):168-79
6. Bally JM, Smith NR, Holtslander L, Duncan V, Hodgson-Widen H, Mpofu C, et al. A metasynthesis: uncovering what is known about the experiences of families with children who have life-limiting and life-threatening illnesses. *J Pediatr Nurs*. 2018 Feb;38:88–98
7. Quittner AL, Goldbeck L, Abbott J, Duff A, Lambrecht P, Solé A, et al. Prevalence of depression and anxiety in patients with cystic fibrosis and parent caregivers: results of The International Depression Epidemiological Study across nine countries. *Thorax*. 2014 Dec;69(12):1090–7
8. Vermaes IPR, van Susante AMJ, van Bakel HJA. Psychological functioning of siblings in families of children with chronic health conditions: a meta-analysis. *J Pediatr Psychol*. 2012 Mar;37(2):166–84
9. Law EF, Fisher E, Fales J, Noel M, Eccleston C. Systematic Review and Meta-Analysis of Parent and Family-Based Interventions for Children and Adolescents With Chronic Medical Conditions. *J Pediatric Psychol*. 2014 Sep; 39(8): 866–886
10. Gan LL, Lum A, Wakefield CE, Nandakumar B, Fardell JE. School Experiences of Siblings of Children with Chronic Illness: A Systematic Literature Review. *J Pediatr Nurs*. 2017 Mar-Apr;33:23-32
11. Green C, Leyenaar JK, Turner AL, Leslie LK. Competency of Future Pediatricians Caring for Children With Behavioral and Mental Health Problems. *Pediatrics*. 2020 Jul;146(1):e20192884
12. Green CM, Leyenaar JK, Tucker A, Et al. Preparedness of Pediatric Subspecialty Fellows to Address Emotional and Mental Health Needs Among Children With Chronic Medical Conditions. *JAMA Pediatr*. 2022 Oct 3;e223451
13. Pickles DM, Lihn SL, Boat TF, Lannon C. A roadmap to emotional health for children and families with chronic pediatric conditions. *Pediatrics*. 2020; 145:e20191324. doi: 10.1542/peds.2019-1324
14. Boat TF, Filigno S, Amin RS. Wellness for families of children with chronic health disorders. *JAMA Pediatr*. 2017 Sep 1;171(9):825–6



## References

15. Cobham VE, Hickling A, Kimball H, Thomas HJ, Scott JG, Middeldorp CM. Systemic Review: Anxiety in Children and Adolescents With Chronic Medical Conditions. *Journal of the American Academy of Child Adolescent Psychiatry*. 2020 May; 59(5):595-618
16. Barlow JH, Ellard DR. The psychosocial well-being of children with chronic disease, their parents and siblings: an overview of the research evidence base. *Child Care Health Dev*. 2006 Jan;32(1):19–31
17. Bally J. A metasynthesis: uncovering what is known about the experiences of families with children who have life-limiting and life-threatening illnesses. *J Pediatr Nurs*. 2018 Feb;38:88–98
18. Sood E, Kenowitz J, Goldberg SW, Butler SC. Normalize-Ask-Pause-Connect: A clinical approach to address the emotional health of pediatric patients with chronic conditions and their families. 2022 Oct 18;S0022-3476(22)00906-4
19. Levine GN, et al. Psychological Health, Well-Being, and the Mind-Heart-Body Connection: A Scientific Statement From the American Heart Association. *Circulation*. 2021 Mar 9;143(10):e763-e783
20. Radecki L. Needs Assessment – Key Informant Interviews Report. American Academy of Pediatrics; 2016 Sep. (Screening in Practices Initiative)
21. Kinebrew, VR, Lawson, C, Rouse, L, Williams, T, Schuler, CL, Lannon, C. The impact of being Black while living with a chronic condition: Inpatient perspectives. *J Hosp Med*. 2023; 1- 4. doi:10.1002/jhm.13059

