



American
Board of
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The
Roadmap
Project

THE AMERICAN BOARD OF PEDIATRICS
FOUNDATION



The
Roadmap
Project

Roadmap to Resilience and Emotional Health for Children with Chronic Conditions and Their Families



This [brief video](#) highlights the power of **four simple words**.





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



Resilience

Opinion

VIEWPOINT

Wellness for Families of Children With Chronic Health Disorders

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Caring for children with a life-threatening or disabling chronic disorder is a challenge that affects, often adversely, the entire family. The prevalence of severe disabilities among children is increasing,¹ with approximately 1 of 20 children having a severe disability.² As this group has lived longer, filled more of the beds in children's hospitals, and demanded increasing ambulatory medical attention, costs of care have increased. Costs to families have also escalated both economically and with regard to socioemotional development. Current child health systems have responded vigorously to the physical health challenges of chronic childhood disease but less consistently to the challenges of proactively supporting the wellness of patients and family members. Pediatric chronic care medicine must more effectively deliver interventions that promote family wellness and resilience.

Disabling chronic disease can be viewed constructively as a serious adverse experience that is unrelenting for many patients and families. A recent international, multicenter study of parents of children with cystic fibrosis determined that 40% of mothers and almost 30% of fathers had elevated symptoms of anxiety and depression during the 3 years after diagnosis by newborn screening.³ Divorce, substance use, and other health problems in family members also interfere with family life and the ability to meet care needs of a child with chronic disease. Maintaining daily treatment regi-

ons providing behavioral support in chronic care programs directly or by referral can be extended in the current care model to identify and respond to risks for problems and to early subclinical problems. Promotion of essential parenting skills is increasingly recognized as effectively delivered in the health care setting⁵ and is as applicable in subspecialty as in primary care.

What dimensions of family life might be addressed with wellness promotion and behavioral health risk prevention? Insufficient and/or poor sleep is well recognized for families of children with chronic diseases. Studies of parents of children who are receiving mechanical ventilation at home show a high rate of parental sleep deprivation, and parents of children with common conditions, such as eczema and asthma, also may often be sleep deprived.⁶ Reasons for inadequate sleep include nocturnal awakening by disorder symptoms, erosion of parent sleep time by care needs of the child, and factors such as worries about health, finances, or other family problems. Assessment of individualized need and interventions for family sleep deficits have potential for enhancing family quality of life and health and improving family coping capacity.

Other dimensions of family life should also be considered in the chronic care model. Physical activity can be promoted using family-focused guidelines or programs to improve stamina, sleep, and strength. Nutrition is often neglected as the result of inadequate time

Current child health systems have responded vigorously to the physical health challenges of chronic childhood disease but less consistently to the challenges of proactively supporting the wellness of patients and families

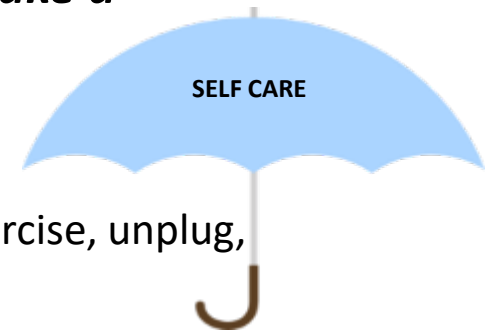
Roadmap's Goal

Increase the resilience and emotional health of children with chronic conditions and their families by:

- Raising awareness among patients and families to 'validate' stress and promote self-care
- Raising awareness among clinical teams to address these issues and provide support
- Providing resources and connections for clinicians and families

What We Have Learned

- ***You don't have to be a mental health professional to make a difference.***
- Begin the conversation early.
 - Support regular self-care for patients and families: sleep, exercise, unplug, mindfulness.
- Use ongoing surveillance as well as screening at specific ages to identify and help those at risk.



Adapted from Stacey Lihn

<https://www.abp.org/foundation/roadmap>

The screenshot displays the website for The American Board of Pediatrics (ABP). The top navigation bar includes links for ABOUT, NEWS, RESEARCH, FOUNDATION, and QUICK LINKS, along with a LOG IN button and a SEARCH BY KEY! field. The main header features the ABP logo and the text "THE AMERICAN BOARD of PEDIATRICS" with the tagline "Certifying excellence in pediatrics – for a healthier tomorrow". Below this are three buttons: "BECOME CERTIFIED", "MAINTAIN CERTIFICATION", and "APPLY FOR EXAM".

The main content area features a large image of five diverse children laughing joyfully. Overlaid on this image is the title "ROADMAP TO RESILIENCE, EMOTIONAL, AND MENTAL HEALTH" in large, bold, white letters. Below the title is a breadcrumb trail: "HOME » ABP FOUNDATION » ROADMAP PROJECT".

On the right side of the page, there is a vertical "FEEDBACK" button. Below the main image, there is a text block on the left and a navigation menu on the right. The text block reads: "Having a chronic condition can cause stress and trouble coping for pediatric patients and their families. It may also make it harder to take good care of themselves or make their symptoms worse." The navigation menu on the right includes "ABP FOUNDATION", "FOCUS AREAS", and "BEHAVIORAL/MENTAL HEALTH".



The Roadmap Project



#Roadmap2Wellbeing

Resources You Can Use

A **Website** where you can learn more about Roadmap and download all of our resources:
<https://www.abp.org/foundation/roadmap>



Scan to view now!



Developing resources you can use...and we're not done!

A **Change Package** with strategies and tools that you can test.



A Change Package

Supporting Resilience, Emotional, and Mental Health of Pediatric Patients with Chronic Conditions and Their Families

Four **Example Conversations** to help clinicians introduce support for emotional health and depression screening.

- ◆ With young child, young teen, and all ages



A **Video** to hear why families and clinicians are partnering with the Roadmap Project:



https://youtu.be/n3j82_1ZTDw

Scan to view now!



Change Package

Concrete, useful tools & strategies



A Change Package

Supporting Resilience, Emotional, and Mental Health
of Pediatric Patients with Chronic Conditions
and Their Families



The
Roadmap
Project

VERSION 2.0
07/2019

What's Needed to Improve Support for Resilience and Emotional Health

1. Patient/family and clinician awareness
2. Care team clinician knowledge, know-how, and confidence
3. Patient/family resilience fostered
4. Peer-to-peer support
5. Surveillance/assessment/screening built into visit and family workflows
6. Resources available and accessible



For Each Component, Resources and Potential Strategies to Test

Potential Changes to Test

DRIVER 1:

Patient/family and clinician awareness of: the impact of a chronic pediatric condition on mental and emotional wellbeing; the need for improved emotional and mental health support including surveillance, screening, treatment, and follow-up; and the potential mitigating role of resilience

Rationale

“You can't get clinician and staff buy-in if they don't understand the impact of a diagnosis on the individuals and families they treat.”

Patients and families:

- Need heightened awareness of the very normal emotional and mental health impacts of the conditions with which they are living
- May have limited awareness of the potential major impact of physical health on mental and emotional wellbeing
- Should be able to expect that they will receive emotional and mental health assessment and follow-up from their care team.

Clinical teams must cover a range of issues including, often, pressing concerns related to physical health. Their clinical training emphasizes the physical aspects of illness, so exposure to emotional and mental health issues is likely lacking.

Potential Resources and Example Changes To Test

- University of Michigan Medicine provides [online information](#) for parents about: how children cope with chronic conditions; how families may be affected; ways the family and child can better cope.
- [6 Steps](#) to Help Move Through a Serious Diagnosis for Your Child.
- The Interactive Autism Network article [Stress and the Autism Parent](#) aims to ‘normalize’ the feelings of stress parents of a child with autism may face, and provides practical tips for addressing it.
- Autism Speaks provides [Family Support Tool Kits](#) (for parents, siblings, grandparents and friends) to help teach more about autism and its effects on families.
- The [Emotional Wellness](#) section of the Cystic Fibrosis Foundation website provides information and blog posts about anxiety, depression and coping for CF patients and caregivers.
- Sisters by Heart and NPC-QIC co-produced [parent brochures](#) to address feelings, coping and support at various time-points in the diagnosis and treatment of HLHS (e.g., at diagnosis, after open-heart surgery).

“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?”

Example Conversations...

Communicating with the Parent/Caregiver of a Young Child with a Newly Diagnosed Chronic Condition

Components of the Conversation

- Recognize that a new diagnosis can raise different feelings and emotions and assure the family that those feelings and emotions are understandable and common
- Emphasize that providing the best short- and long-term care for a child with a chronic condition involves not just the physical aspects of health, but the mental and emotional health needs of the child and family
- Incorporate individual/family strengths to promote resilience and emotional health
- Encourage the family to practice coping strategies and self-care, including for any siblings
- Acknowledge potential stigma surrounding eating for help
- Provide education about what a mental health provider can do (not all families understand behavioral health and some may believe that it is for those with severe problems)
- Provide educational materials and anticipatory guidance based on family's expressed needs
- Offer peer mentoring/family support opportunities

Example Conversation

Families have told us that getting a diagnosis of [condition] can be an overwhelming and challenging time with lots of different reactions and feelings. For some, it might be a relief to finally put a name to the symptoms their child has had and to begin creating a plan, with the health care team, about how to help. For others, a diagnosis prompts fears or uncertainty about how this condition will affect their child's life, themselves, and other family members.

Tell me, how are you doing today?

Because I'm a doctor who cares for children with [condition], it may feel like we talk a lot about the [condition/affected organ or organ system] at our visits. Please know that we care about what's going on with your child's emotional health, too. We understand that [condition] can affect many aspects of life, not just the physical part.

We also care about what's going on with you and your family. Thinking about the health and well-being of your whole family is an important part of [condition]. You can expect us to ask regularly about how you, your family, and your child are doing when you come to clinic.

In the time that we've known each other/although we haven't known each other for very long, I have observed/hence that you [describe individual/family strength or aspect of resilience]. That can be so helpful in [child's] care/an excellent strategy for helping you and your family cope. But we also know that even with those strengths, families sometimes have concerns or need some extra support or assistance. That's ok, common, and to be expected. Asking for help is one of the best things you can do for yourself and your child when you need it. It might be now, it might be later - or both. We are here and will be here every step of the way. We want you to ask any questions, and to let us know any time that you would like some extra help.

This might be a lot to take in at once...please don't feel that you need to remember everything. It took me several years to learn all of this, I don't expect you to remember it all today. Some families

- With a parent/caregiver of a young child with a newly diagnosed chronic condition
- With a young teen and a parent/caregiver about a newly diagnosed chronic condition
- At a routine surveillance visit with an established patient/family
- Introducing depression screening for young teens with a chronic condition

*Available: slide deck
Coming: video "how-to"s*

Dissemination and Implementation

Changing the Outcome

- Build will and raise urgency
- Provide education and tools
- Execute and implement

Adapted from Don Berwick

Disseminate and Implement

- We are early (18 months in)
- Target audiences
 - Learning Networks (collaborations focused on chronic conditions)
 - Trainee groups (e.g. residents, fellows) and faculty
 - Key stakeholder groups (e.g. childrens hospitals)
 - Disease specific organizations



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