

Carole Lannon, MD, MPH ♦ Laura E. Peterson, BSN, SM ♦ Jill Plevinsky, PhD ♦ Diane Pickles ♦ Wallace Crandall, MD, MMM ♦ and our patient, parent, network, and American Board of Pediatrics colleagues

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Background

- Living with a chronic pediatric condition is challenging, and can cause stress, altered coping, and lasting impacts on child and family emotional health. Emotional health support often lags physical care.
- The prevalence of behavioral and mental health conditions in children, adolescents and young adults is significant.
 - 65% of pediatricians surveyed by the American Academy of Pediatrics indicated that they lacked training in recognizing and treating mental health problems.
- The American Board of Pediatrics (ABP) identified addressing mental health needs of children and families as a strategic priority in 2014.
- In February 2017, the ABP chartered the Roadmap Project.



After attending the ABP September 2016 meeting "Partnering with Patients and Families to Advance Quality", three parents wrote to the ABP CEO:

"We believe there is a valuable opportunity across chronic disease networks to address the important issue of emotional support and mental health for children with chronic illness. If the ABP were willing and able to invest resources, we might be able to truly generate a roadmap for new strategies and interventions.

With the rich working group that was in the room last week and parents and patients, you've got all the right players to co-design something that will benefit patients and families."

Project Aim

The objective of the Roadmap Project is to increase the resilience, emotional and mental health of pediatric patients with chronic conditions and their families by:

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

Results

We have developed a website; a video; a Driver Diagram; a Change Package with practical tools to raise awareness, select changes to test, and metrics to assess progress; and four Example Conversations resources to help clinicians introduce mental health support and screening activities. Many of the materials can be used for teaching individual sessions.

The Change Package is a concise and practical document that includes ideas and inspiration for teams seeking to apply quality improvement methods to increase the effectiveness and efficiency of their care processes and outcomes. We are training individuals to present and broadly share the Change Package across collaborative learning networks, relevant patient/family and clinician specialty organizations, and among subspecialty clinicians. The Change Package and a number of its components can also be used for improvement efforts in continuity clinics, training sites, fellowship settings, and subspecialty clinics.

Partners



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Multidisciplinary Team

The Roadmap Project is working with:

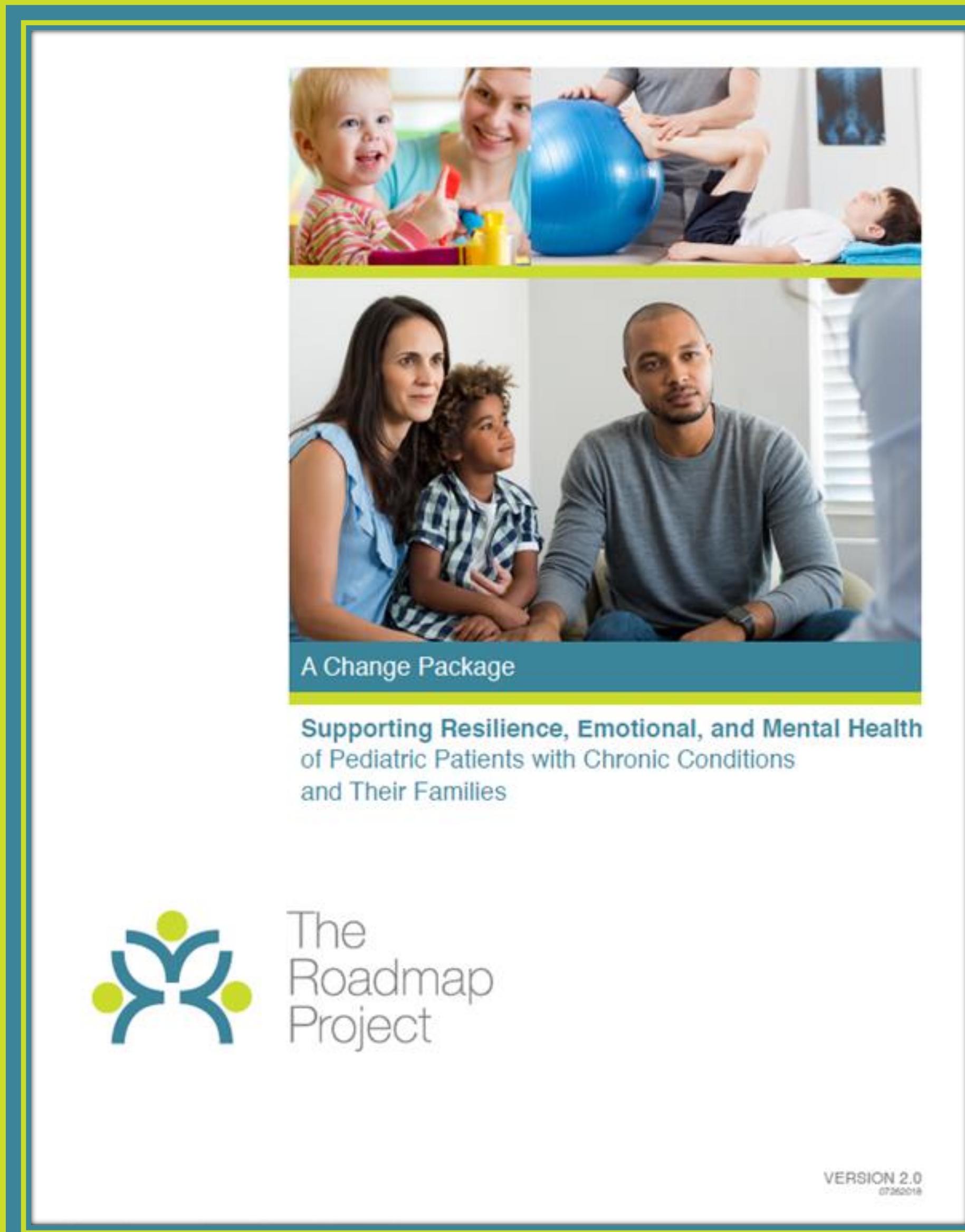
- Patients and parents across chronic conditions communities
- Subspecialty clinicians, trainees, and fellows
- Pediatric psychologists
- Learning Networks
- Pediatric stakeholder organizations (residency and fellowship training programs, Committee on Pediatric Subspecialties, the American Academy of Pediatrics, pediatric board chairs, the National Academy of Medicine)

Project Design/Strategy

Using evidence-based engagement and peer production strategies with patients and parents from nine Learning Networks focused on chronic conditions (autism, chronic kidney disease, complex congenital heart disease, cystic fibrosis, inflammatory bowel disease, juvenile idiopathic arthritis, perinatal collaboratives focused on prematurity, sickle cell disease, and type-1-diabetes), we:

- Systematically investigated patient/family needs for support for emotional health and resilience;
- Identified strategies for addressing these needs from literature review, current network initiatives and other relevant organizational efforts;
- Conducted structured discussions with parent and patient partners from the Learning Networks and other organizations;
- Conducted an external environmental scan, including a literature review, to determine what clinician/patient/parent experts, researchers, and thought leaders in this area recommend as ideas for changes to test.

Resources Developed



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 asking 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) sense 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

Lessons Learned

Key messages for patients, families, and clinicians:

- It's not always easy living with a chronic health condition. Yet resilience is not uncommon. 'Simple' strategies to empower patients can go a long way.
- Psychological distress and resilience are not mutually exclusive.
- You don't have to be a mental health professional to make a difference.
- Annual depression screening is unlikely to be successful unless it is part of ongoing surveillance and support activities

Challenges due to the breadth of the topic:

- The potential mental and emotional health risks and opportunities for enhanced awareness, coping, and support vary across the range of pediatric chronic conditions.
- Needs of individual patients/families living with a given condition can vary dramatically over time.

Conclusions

This project used a cross-network community of patients, families and clinicians to develop a set of resources (including a video) and implementation strategies that can be used to raise awareness regarding the emotional toll of dealing with chronic illness, and to identify practical strategies and tools for supporting the emotional and mental health needs of children with chronic illness and their families.

Participating Networks

