

Addressing the emotional toll of pediatric chronic conditions

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Dr. Boat, Cincinnati Children's, is a co-author of today's report in *Pediatrics*.
Credit: Cincinnati Children's

Be it autism, sickle cell or other life-disrupting health conditions, being

the parent of a child with a chronic condition takes a psychological toll. For too many families, however, emotional and behavioral health support has been far too difficult to obtain.

Now, a project led by experts at Cincinnati Children's reports on the progress made since 2017, when the American Board of Pediatrics Foundation launched its "Roadmap Initiative" to increase resilience and [emotional health](#) within families of children with chronic conditions. The report, published today in *Pediatrics*, was co-written by parents living through this experience. It also provides a set of tools that any pediatrician can use to improve how they communicate with families about emotional well-being.

"There have been numerous successful efforts to improve the physical care of pediatric patients living with chronic conditions. We rightly celebrate our therapeutic achievements," says Tom Boat, MD, a long-time leader in pediatric medicine at Cincinnati Children's.

Boat co-authored the report in *Pediatrics*. He also is a member of the National Academy of Medicine, where he recently chaired a report on fostering healthy mental and [emotional development](#).

"However, more children are living longer with disabling and life-threatening chronic disorders.

There has not been commensurate focus on enhancing emotional health and building resilience," Boat says. "But we're beginning to understand that if you don't support emotional health of children and families, everything else is at risk for falling apart."

Parents Calling for Change

Shortfalls and limitations to the availability of [mental health](#) services in

pediatric settings have been documented for many years. The Roadmap Initiative traces its roots to September, 2016, when more than 30 parents attended and addressed a meeting of the American Board of Pediatrics. Despite coping with extremely different [health conditions](#), many of the challenges families face are universal.

"The overriding theme was of being overwhelmed, with our child's condition affecting every aspect of our lives, and everyone to whom we are connected," according to parent co-authors Diane Pickles and Stacey Lihn.

"There are multiple stressors and often a lack of consistency in daily life for families of children with chronic conditions. There are impacts on friendships and social life for children and parents, and educational impacts for children who miss school and/or have neurological impacts from their disease," the parents say. "There can be behavioral challenges, either from the child with the health issue or siblings. For parents, there is little time to exercise, eat right, or give enough attention to your other children. We feel isolated and as if our [family](#) and friends don't truly understand."



Dr. Lannon, Cincinnati Children's, is a co-author of today's report in *Pediatrics*.
Credit: Cincinnati Children's

Be it the stigma that can be attached to mental health, or feelings of embarrassment or inadequacy, many parents may be afraid to say they are struggling. However, pediatricians can open doors for families simply by beginning a conversation.

LaToshia Rouse, the mother of a set of triplets born prematurely and a son with autism, recalls being shocked when a pediatrician asked her how she was doing. Now she likens the importance of mental health support for [parents](#) to the oxygen masks that drop from airplane overhead consoles during emergencies. Passengers are reminded to put their own mask on before helping their children.

"What I realize now is that until mamma has what she needs, that baby can never thrive," Rouse says.

Support for Pediatricians

The new report points out that experts have identified "resilience-based interventions" that can help families, such as strengths-based cognitive-behavioral therapy and mindfulness techniques. The co-authors also acknowledge that many pediatricians have been unaware of these resources and may also be reluctant to begin discussions that they fear may go beyond their direct expertise.

"A crucial message to all pediatricians, specialists and generalists, is that you don't have to be a mental health professional to make a difference," says Carole Lannon, MD, MPH.

Lannon is the Senior Faculty Lead of the Learning Networks Program at the James M. Anderson Center for Health Systems Excellence at Cincinnati Children's. She's also the Senior Quality Advisor for the American Board of Pediatrics.

"Parents emphasize they don't expect their pediatricians to be mental [health](#) experts. But the pediatrician's interest and support is tremendously valued," Lannon says. "Validating the stress patients and families feel can open the door to discussion."

To help more pediatricians begin such conversations, the Roadmap Initiative offers a number of free tools and resources (available at: www.abp.org/foundation/roadmap). Looking ahead, teams from Cincinnati Children's and eight other children's hospitals have formed a pilot learning collaborative to test the feasibility of specific practice changes.

Boat predicts that many caregivers will find they can provide more help without being full-blown psychiatric experts.

"If we start working with families from the time of diagnosis—very early—so that they begin to understand that their resilience is important for their child, that their emotional well-being is crucial to outcomes for their child, then I think that the care team can take responsibility for partnering with families to achieve this," Boat says.

More information: Diane M. Pickles et al, A Roadmap to Emotional Health for Children and Families With Chronic Pediatric Conditions, *Pediatrics* (2020). [DOI: 10.1542/peds.2019-1324](https://doi.org/10.1542/peds.2019-1324)

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