



A Change Package

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



The
Roadmap
Project



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Background and Purpose

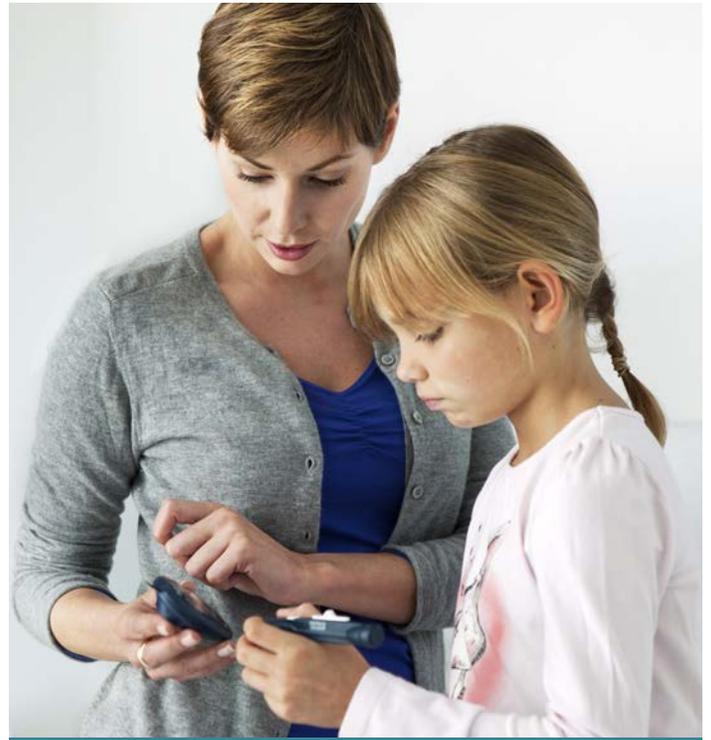
Recognition of behavioral and mental health conditions in children, adolescents and young adults has increased over the last several decades.

However, as recently as 2013, 65% of pediatricians surveyed by the American Academy of Pediatrics (AAP) indicated that they lacked training in recognizing and treating mental health problems. Addressing mental health was an initiative prioritized by the Strategic Planning Committee (SPC) of the American Board of Pediatrics (ABP) in 2014. Looking for and acting on opportunities to advocate for patients and families regarding mental health was one of the SPC recommendations.

Many children and adolescents living with chronic conditions and their families navigate extremely challenging issues that can cause stress and alter coping mechanisms, potentially leading to exacerbations in their conditions, challenges in self-care and treatment adherence, delays in reaching developmental milestones, and significant mental health impact that can persist into adulthood.¹⁻⁹ Likewise, chronic conditions in children can have substantial negative impact on the mental, physical, and emotional health of family members, including parents, siblings, and other caregivers.^{4,9-16}

There have been numerous successful efforts to improve the *physical* care of pediatric patients living with chronic conditions, but less focus on building resilience and enhancing emotional and mental health. More focus is also needed on maintaining caregiver health and wellbeing and teaching resilience skills. As noted recently, “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.”¹⁷ This Change Package aims to help enhance awareness of and ability to address these issues.

There are some important considerations for users of this Change Package. First, there are a range of pediatric chronic conditions; the unique mental and emotional health risks and opportunities for increased awareness, coping, and support can vary across diagnoses. For example, there may be common challenges faced by patients with autism and patients with cystic fibrosis, as well as key differences. Additionally, the



“My only expectation is that our physician understands that living with chronic illness is riddled with stress and burden, but having (and being given) the medical tools and knowledge by a provider, to address mental health from onset, is crucial in reducing those issues. Our ultimate goal should always be to have a happy and healthy child.”

- Mother of two daughters with type 1 diabetes

needs of individual patients and families living with a given condition can vary dramatically over time. For example, an 8-year-old newly-diagnosed with type 1 diabetes will face different emotional challenges than an 18-year-old who was diagnosed as an infant and transitioning from pediatric to adult care. For that reason, the potential changes included in this document will require customization for specific conditions and populations of patients and families.



How was this Change Package Developed?

This Change Package was inspired by and grounded in tools, methods and approaches already being developed or tested with ten Learning Networks for chronic pediatric conditions ([see page 19](#)). The content was also informed by a series of structured discussions with patient and family partners living with chronic conditions from the Learning Networks and other organizations. We also 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.

The strategies described here have not all been tested extensively in a group of clinical practices. Rather, 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 version of the Change Package is Learning Network teams working to improve care for patients and families living with chronic pediatric conditions, including clinicians, improvement specialists, patients and parents. Providing excellent emotional and mental health support requires multi-disciplinary collaboration. Pediatricians and pediatric specialists participating on these teams may not be the primary interventionists, but must be knowledgeable and supportive of interdisciplinary efforts.¹⁷



A Note About Definitions

For the purpose of this Change Package:

Pediatric encompasses patients from birth through young adulthood.¹⁸

Chronic condition is “any condition that requires ongoing adjustments by the affected person and interactions with the health care system”.¹⁹

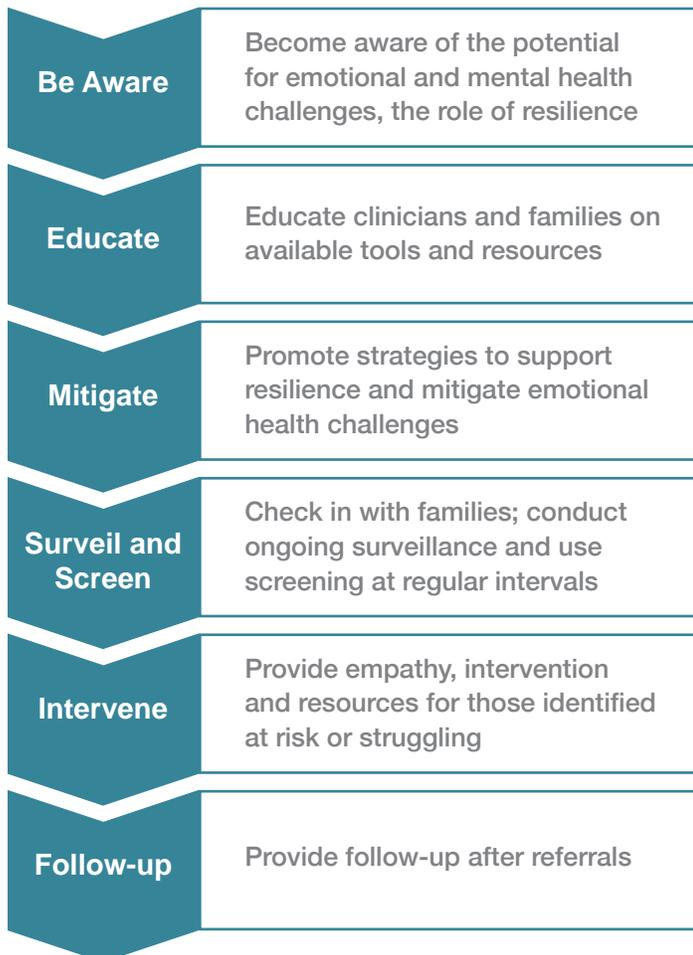
Natural supports are personal associations and relationships (e.g., friendships, family relationships) that enhance the quality and security of life for people, and may provide assistance, organically, for everyday living.

Learning Networks are communities of patients, families, clinicians and scientists who use data for clinical care, improvement, discovery, and innovation.



Setting the Stage

Supporting the mental and emotional health and resilience of pediatric patients with chronic conditions and their families follows a continuum.



Patient, Family and Clinician Awareness

It is important to acknowledge the stresses of pediatric chronic conditions for patients and families. This can help to destigmatize and 'normalize' the stresses of managing chronic conditions.

Clinician Education

Clinical training typically emphasizes the physical aspects of illness, so additional exposure to resources for providing care and support for mental and emotional health issues will be needed.

Resilience to Mitigate Challenges

Despite experiencing stress, families also have strengths, capabilities, and protective factors such as cohesion, humor, and spiritual and cultural beliefs. Approaching families from a strengths-based perspective helps build trusting relationships and fosters a proactive approach to resilience.

Surveillance and Screening

Mental and emotional health assessment should be a part of routine care, beginning at the time of diagnosis. Adding a 'check-in' about how the patient and family are coping at most visits makes it part of an ongoing surveillance system. This approach also helps 'normalize' mental health assessments for families. Conduct regular screenings for all, and targeted screenings for families that have known risk factors or are distressed.

Intervention and Follow-up

Targeted, problem-focused treatment for patients/families with high levels of risk factors or who report/display emotional distress can reduce symptoms and prevent ongoing or escalating distress.²⁰ Referrals and follow-up activities should be facilitated whenever possible by co-located, embedded or local supports such as social workers, mental health professionals, care coordinators, and/or parent navigators.²¹



What Do We Already Know?

Selecting changes to test in Learning Networks is evidence-informed, and expert opinion driven. In developing this initial Change Package, we undertook an environmental scan to identify:

- published evidence, and
- what clinician/patient/parent experts, researchers, and thought leaders in this area recommend as ideas for changes to test, especially for areas without strong evidence.

What are Effective Coping Interventions for Patients, Parents and Families?

The body of published evidence regarding interventions for emotional/mental health in children with chronic conditions or their families is growing. However, there is more information available about certain pediatric conditions (e.g., cancer, diabetes, children born prematurely) and less so about others. Most studies have been conducted with children; fewer have evaluated the psychosocial impact on siblings or parents. Despite these limitations, we identified a number of effective coping strategies.

Encouraging caregiver self-care

Family caregivers are less likely to practice preventive health-care and self-care behavior.²² Therefore, encouraging self-care strategies, such as sufficient sleep, exercise, healthy eating, stress management, and asking for and using social support is important. In particular, parents of young children often lack support in times of stress.²³

Cognitive behavioral therapy (CBT)

Typically provided over a series of individual or group sessions, CBT has been shown to be effective in bolstering coping and managing the psychological components of chronic illness for children and adolescents^{9,24-28} and their parents.²⁵ Effectiveness for siblings of children with a chronic condition is less clear.²⁹

Mindfulness-based strategies

Relaxation, meditation and mindfulness training have been shown to be effective to manage stress, depression and anxiety, and can be used by both children and parents.³⁰⁻³²



Connecting with peer support resources

Peer support allows people facing a common challenge/health condition to share knowledge and experiences – including some that many health workers do not have.³³ This may include:

- emotional support - information that one is loved and valued, and connected to others
- informational support - helps solve problems and find tangible services and resources
- instrumental or tangible support at times of extreme stress.³⁴

Peer support programs with a social support component can improve quality of life outcomes for adolescents with chronic illnesses.³⁵ Qualitative studies strongly suggest that parents of children with a chronic disabling condition perceive benefit from peer support programs.³⁶ However, quantitative studies provide inconsistent evidence of positive effects. Providing peer support to parents of NICU infants increased confidence and well-being, coping, perception of social support, and reduced parental stress, anxiety, and depression.³⁷ Additionally, virtual peer support communities have been shown to have a positive impact, including improved coping and self-management.^{38,39}



Religious/spiritual coping strategies

A strong sense of spirituality has been associated with helping patients cope with life-threatening and chronic illness.⁴⁰ For example, more frequent use of positive spiritual coping may buffer adolescent patients with cystic fibrosis or type 1 diabetes from developing depression and maladaptive coping strategies over time.⁴¹

Problem solving therapy (PST) / problem solving education (PSE)

PST/PSE involves didactic instruction in effective problem-solving skills, followed by modeling, behavioral rehearsal, and performance feedback. In a Cochrane review of psychological interventions for parents of children and adolescents with chronic illness, PST improved parent adaptive behavior and parent mental health.²⁷ In a meta-analysis, PST had a small but significant effect on parent mental health post-treatment and at follow-up.⁴² As a specific example, six brief PSE sessions reduced parental stress and maternal depressive symptoms in mothers during the period immediately following a diagnosis of autism spectrum disorder.⁴³

Camp

When it is possible, attending a disease-specific camp can allow children to enjoy a camp experience without concern about or preoccupation with their underlying disease or associated stigma, providing improvements in well-being, self-perception, and emotional outlook.⁴⁴⁻⁴⁶ However, longer-term follow-up studies are needed. Camp may also be a source of respite for caregivers.



Can Fostering Resilience Help?

There is increasing awareness of protective factors and their ability to ameliorate some of the emotional and mental health challenges involved in living with pediatric chronic conditions. Helping patients and families identify, access and build on their own strengths, such as resilience, can be a powerful tool.^{47,48} Family-centered and mindfulness-based approaches can promote resilience and self-regulation of stress and emotions.⁴⁹

Should We Be Routinely Screening?

A number of evidence-based guidelines and position statements from professional medical societies and disease-specific organizations recommend routine emotional and mental health screening of patients and/or families⁵⁰, including for children with congenital heart disease^{51,52}, people with diabetes and their families⁵³, children with cancer⁵⁴ and their parents⁵⁵ and siblings¹⁵, and individuals with cystic fibrosis and their parents.⁵⁶ Screening allows identification of potential problems as proactively as possible, and provision of evidence-based intervention to ameliorate future development of emotional and behavioral concerns.



What Do We Want to Accomplish?

The high-level or “global” aim for this project is:

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

Each quality improvement (QI) team will also set aims to guide their work. One way to do so is to brainstorm what they would like to be able to say about what they do to meet the emotional and mental health needs of patients and families that they cannot say today.

How Will We Know That a Change is an Improvement?

Some potential aims and related measures to assess progress toward achieving them are listed in Table 1. These measures have not been tested; they are examples and initial ideas based on literature, parent and patient feedback, and ongoing work in Learning Networks.

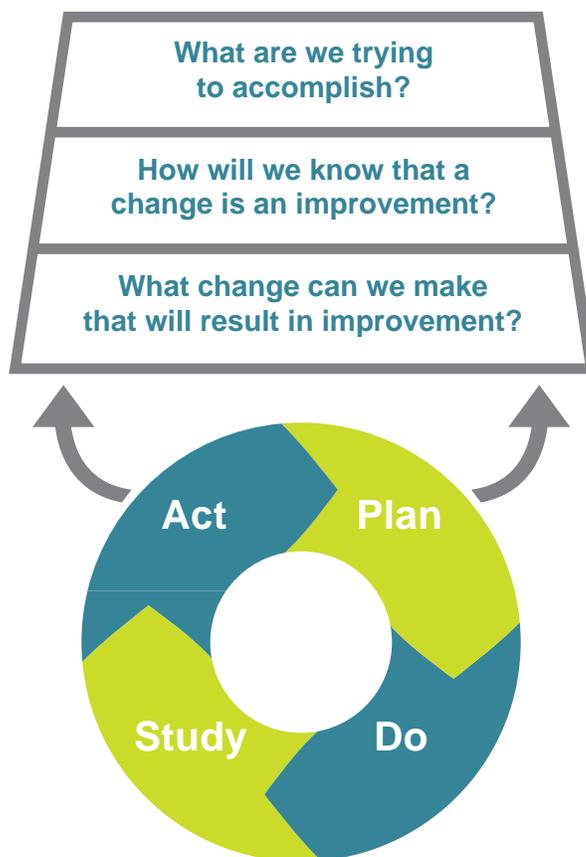


Table 1. Example Improvement Aims and Measures

Area of Focus	Aim	Measure
Awareness	By June 1, 2018, 100% of families of patients with newly-diagnosed [condition] will be able to relate that there are potential emotional and mental health impacts of the condition.	% of families of patients with newly-diagnosed [condition] who can relate that there are potential emotional and mental health impacts of the condition.
	By October 31, 2018, 50% of clinic staff will report they understand the importance of discussing with patients and families how they are coping.	% of clinic staff who report they understand the importance of discussing with patients and families how they are coping.
Resilience	By August 1, 2018, 75% of parents of children with [condition] will have a documented discussion focusing on tools and strategies that can help them cope.	% of parents of children with [condition] who have a documented discussion focusing on tools and strategies that can help them cope.
Screening	By September 15, 2018, 90% of [condition] patients 12+ years old will receive an annual screening for depression.	% of [condition] patients 12+ years old who receive an annual depression screening.
Intervention	By November 30, 2018, 100% of families with identified mental health needs will be referred to a mental health professional.	% of families with identified mental health needs that are referred to a mental health professional.

A Key Driver Diagram to Guide Your Efforts

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

Following the driver diagram are a range of specific possible changes to test to optimize resilience and emotional and mental 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 current 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 improvement teams decide what to try based on the area of focus they would like to address. Many of the changes will need to be customized to meet the needs of specific populations of patients and families.



“I think having physicians who have a value for mental health and are willing to initiate hard conversations with their patients are super important. When I see clinicians who value mental health, I also find these people are more likely to recognize our overwhelming treatment burden, people who want to see the challenges we face as a family and people appreciate my child’s need for comfort/pain management and safety when it comes to medical procedures.”

- Mother of a son with cystic fibrosis



A Key Driver Diagram to Guide Your Efforts

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

Key Drivers

Change Concepts

1 Patient/family and clinician awareness

Awareness for Patients and Families

- Match newly-diagnosed patients/families with a peer mentor to help orient them to day-to-day life with their condition
- Provide tip sheets, weblinks and other educational materials for patients and families
- Co-produce blogs/newsletters with patients/families about emotional and mental health
- Schedule dedicated education visits for newly-diagnosed patients
- Hold regular, ongoing educational sessions for families (e.g., Education Day)
- Develop strategies to address the stigma of asking for help

Awareness for Clinicians

- Share patient and family stories
- Use language that acknowledges the stresses of living with/parenting a child with a chronic condition
- Conduct clinic training sessions co-led by psychosocial professionals (when possible, trained in the specific disease), parents, and patients
- Provide tip sheets and other job aids for clinic staff
- Program reminders and prompts to address emotional and mental health concerns in the electronic health record (EHR) and/or other visit documentation
- Appoint a clinic champion to raise awareness about the need to address these issues and to evaluate and make changes to the process as needed

2 Care team clinician knowledge, know-how, and confidence

- Provide clinic training sessions co-led by psychosocial professionals (when possible, trained in the specific disease), parents and patients
- Develop scripts to help all team members increase comfort with discussing emotional and mental health issues and explaining basic psychosocial aspects to patients/families
- Ask patients and families to describe “ideal” conversation starters about emotional and mental health issues so clinicians can test ways to start discussions
- Provide training in knowing when to refer
- Teach active listening, “Hear and Understand”
- Recognize that parents want to be viewed as capable, may hesitate to share stress
- Ask open-ended questions (“How are you?” not “Are you ok?”; “How can I help you?” not “Do you need anything?”)

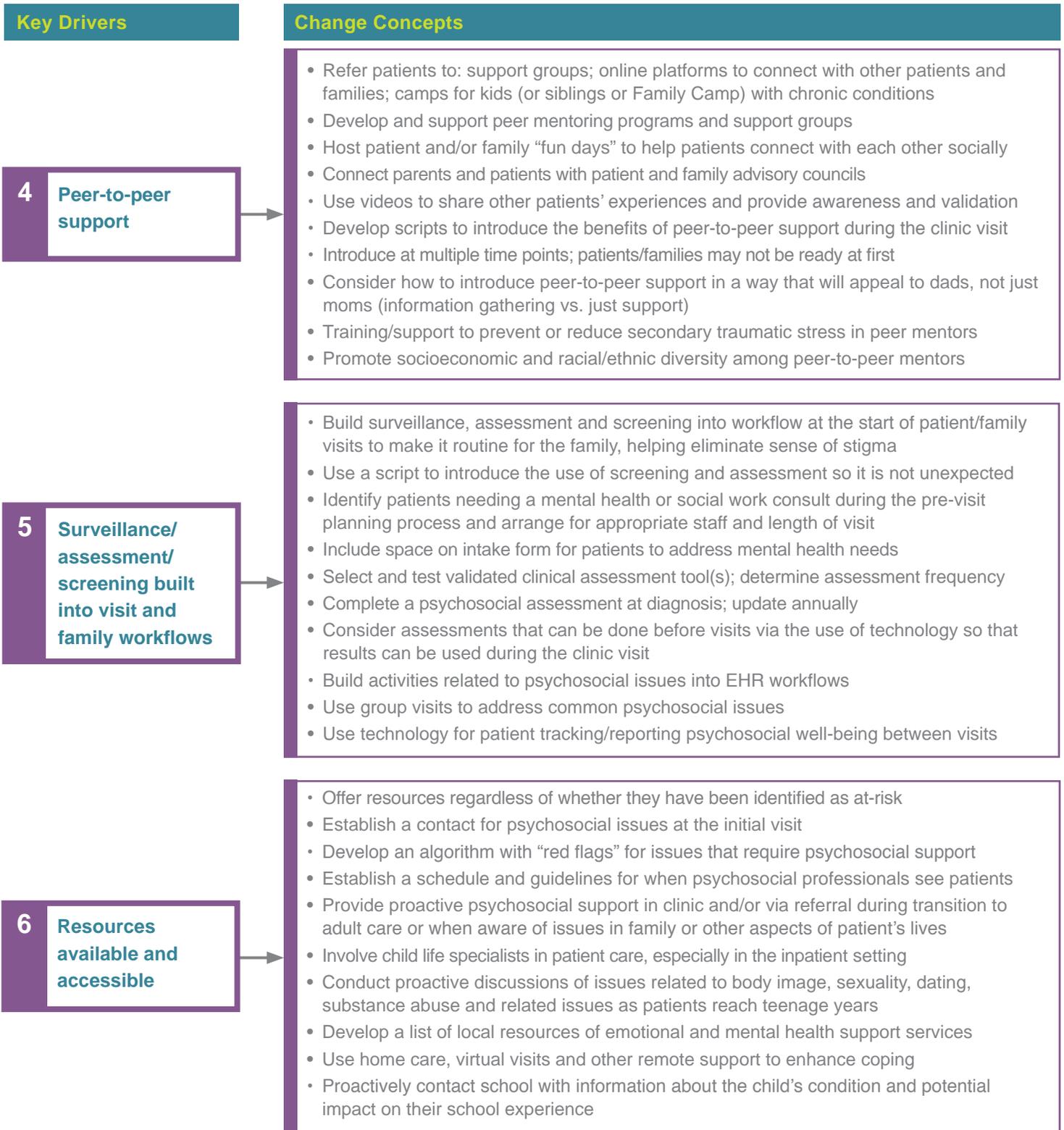
3 Patient/family resilience fostered

- Share stories of hope from other patients and families
- Recommend age- and ability-appropriate techniques for children and family members for mindfulness-based stress reduction, healthy coping, and communication
- Provide resources to develop a child’s awareness/regulation of his/her own feelings
- Increase awareness of cultural variations and different ways families show strength
- Recognize (and reinforce) when patients and parents are doing a good job of self-care



A Key Driver Diagram to Guide Your Efforts

Key Driver Diagram – Page 2



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).
- ➔ The Pediatric Congenital Heart Association provides information on [Promoting Mental Health for Parents of Children with Heart Conditions](#)
- ➔ ImproveCareNow Patient Advisors write [blog posts](#) to share their stories about emotional and mental health while living with inflammatory bowel disease.

“In the 22 years my son has been cared for at one of the country’s leading children’s hospitals, NO ONE has ever asked my son or me how we are coping... I think his emotional health has been a more difficult issue for our family than his severe congenital heart disease”.

“That has been our experience as well. Our son is a teenager with cystic fibrosis, and we have never been asked how we are doing”.



Potential Changes to Test

DRIVER 2:

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

Rationale

“When I bring it up, oftentimes, doctors don’t know what to do with my questions.”

Even if clinicians are aware of the need to address the emotional and mental health aspects of care for chronic conditions, they may not have the training and exposure needed to do it reliably and with confidence.

They need both the knowledge (what are the facts?) and know-how (how does one put one’s knowledge to use?) to be able to make addressing emotional and mental health issues part of their practice, and to do so in a way that is productive and helpful to patients and families.



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

Parents experience profound and pervasive uncertainty. Parental hope is critical to their experience and supports caregiving.¹³

Potential Resources and Example Changes To Test

- ➔ The American Academy of Pediatrics provides a number of resources:
 - [The Mental Health Practice Readiness Inventory](#) helps practices assess the extent to which their office systems support mental health practice. Designed for use in primary care practices, it may also be helpful for pediatric subspecialty teams.
 - [Working with Families](#) is a set of resources that providers can share with families who have concerns or questions about mental health and children.
 - Tools for [implementing mental health priorities in practice](#)
- ➔ [Effective Child Therapy](#), developed by the American Psychological Association, is a tool for guiding therapy recommendations, including levels of evidence, what child psychologists do, and how to locate one.
- ➔ The Society of Pediatric Psychology provides [evidence-based practice resources](#) (including information on the prevalence, etiology, consequences, and evidence-based psychological assessment and treatment) for common pediatric conditions that could be useful for community therapists to access when working with a patient with a chronic illness.
- ➔ [‘Simple’ changes](#) can help clinicians become more confident in discussing emotional and mental health with patients and families.
- ➔ Attend psychosocial educational sessions and training offered at national medical meetings.
- ➔ Acknowledge the uncertainty: “I wish someone would have said not only ‘We don’t know’ but also ‘We don’t know and that must be really hard for you to live with.’ Recognizing the burden of the uncertainty would have made it less powerful.”⁵⁷



Potential Changes to Test

DRIVER 3:

Patients and families are approached from a strengths-based perspective; care teams partner with them to identify assets and strategies on which they can draw to foster resilience

Rationale

“Psychological distress and resilience are not mutually exclusive”

“Supporting coping and resilience can prevent psychosocial distress from turning into traumatic stress”

Age-appropriate health-promoting activities can improve the abilities of children and adults to cope with and adapt to adversity in their lives, such as the stresses that may come with a pediatric chronic condition. And adults who strengthen these skills in themselves better model these behaviors for their children.⁵⁸

Resilience-based interventions can help families:

- Identify their strengths
- Recognize protective factors and resources they can use and build on within their family and the environment
- Provide opportunities to practice strategies to improve coping and family functioning⁴⁷

“As doctors and nurses, we are generally terrible at self-care and experts at compartmentalizing”

Caring for children with chronic conditions and their families can also be stressful for clinicians. Improving clinician mindfulness and resilience is associated with their ability to provide more relationship-centered care.⁵⁹

Potential Resources and Example Changes To Test

- ➔ The Children’s Hospital Colorado [toolkit for parents of children who are chronically ill](#) includes sections on [building resilience in families](#), and [stress management for parents](#).
- ➔ The American Psychological Association’s [Resilience Guide for Parents and Teachers](#) provides tips for building child resilience, by age. It isn’t specific to chronic conditions but many of the suggestions likely apply.
- ➔ [Books of Hope](#) are available for hypoplastic left heart syndrome, cystic fibrosis, juvenile arthritis, and inflammatory bowel disease. Written by parents and patients, they are designed to give families strength after the diagnosis of their child.
- ➔ JDRC provides a [Bag of Hope](#) for children newly diagnosed with type 1 diabetes.
- ➔ Lucille Packard Children’s Hospital provides a list of [Single Ventricle Patient and Family Resilience Resources](#) including mindfulness-based techniques.
- ➔ Periods of [respite](#) - planned or emergency care provided to a child with a chronic condition in order to provide temporary relief to family caregivers – can also foster resilience in families.
- ➔ Several mindfulness techniques that children and adolescents can practice at home are provided [here](#).
- ➔ The American Medical Association’s [StepsForward™](#) program has free, self-paced modules to help physicians increase their resiliency in clinical practice.
- ➔ The American Academy of Pediatrics [Resilience Curriculum](#) (scroll down to Part D) has cognitive, occupational, emotional, interpersonal, spiritual and self-care strategies to enhance personal resilience for healthcare providers.



Potential Changes to Test

DRIVER 4:

Patients and families have access to peer-to-peer support as appropriate

Rationale

“Sharing family perspective ... can help families to know that they are not alone and ‘normalize’ the challenges and feelings of other families.”

While emotional and mental health support from the health care system is essential, peer support is an invaluable way to get oriented to the possible challenges associated with a chronic condition, learn how to navigate care systems, and potentially, begin the journey to eventually providing peer support to others.

Potential Resources and Example Changes To Test

- ➔ Camps for children with chronic conditions (and/or their siblings) can provide an opportunity to “just be a kid” and to interact with other children with a similar condition. A teen describes what he gained from attending [Camp Oasis](#).
- ➔ Peer mentoring programs are available for a number of pediatric conditions. For example:
 - [MedMentor](#) of Greater Cincinnati connects children and adolescents ages 10-19 with a chronic health condition with adult patients.
 - The Children’s Mercy [Parents Offering Parent Support \(POPS\) program](#) trains parent volunteers to mentor other parents through the challenges of living with chronic kidney disease and other conditions.
- ➔ [Coping Club](#) provides a library of videos ‘for kids by kids’ to help them better understand their medical condition and share ways in which they have handled the stressors.
- ➔ The Arthritis Foundation provides a number of ways in which parents and children with Juvenile Arthritis can [Meet Other Families](#).
- ➔ Sisters by Heart sends [care packages](#) to families who have recently learned their child has HLHS to let them know that there is hope and they are not alone.
- ➔ The IBDevoted team, comprised of parents of IBD patients at Cincinnati Children’s Hospital Medical Center, sponsors ‘Gutsy Girls’, a social group for teen girls with IBD that meets to “hang out, play games, and participate in activities like mini-golf. While everyone has IBD, it is not the group’s main focus”.

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Potential Changes to Test

DRIVER 4: (continued)

Patients and families have access to peer-to-peer support as appropriate

Rationale

“I am a member of a closed Facebook page for my daughter’s disease...I find that group to be very effective for connecting families around the world with her rare, genetic disorder.”

Online mechanisms (e.g., chat, social media) also exist for peer support. A number of parents have indicated they have found this support very helpful. Mental health clinicians counsel to approach these resources cautiously. Considerations include:

- Whether the group is monitored and by whom to ensure members are posting appropriate content and to ensure emotional and physical safety for members.
 - Ideally a monitored site is able to follow-up and remove inappropriate content and takes action to ensure safety if suicidal ideation or self-harm is possible.
- Qualitative research suggests that many do not wish to be identified with their health condition in social media...that is where they want to be ‘normal’.
- Frequent “posters” on social media may be struggling physically/emotionally and have more time to post due to limited social/work/school. Their posts may give readers a skewed impression.

Potential Resources and Example Changes To Test

- ➔ **Smart Patients** is a series of online communities where patients and their families learn from each other. Current communities include chronic conditions (e.g., cystic fibrosis, congenital heart defects, inflammatory bowel disease) as well as those for Young Adults, Transition to Adult Care, and Caring for a Sick Child.
- ➔ “When my daughter was initially very ill, I used **Caringbridge** on a daily basis to update our family and friends. It was password protected so I knew that those who were reading the updates were not the general public. [It was] incredibly useful at times of great stress because it is one location to give updates and it takes away the need to make many phone calls or send emails updating everyone. It also gave us a great sense of community when people responded. It let us not feel as alone...It also now serves as a helpful documentation of our family’s journey (both factual and emotional in content).”
- ➔ **Linked by Heart** provides a password-protected secure database for HLHS families to connect and network nationally, and Regional Coordinators (HLHS mothers) who help locate other families in the same situation.
- ➔ Provide guidance / have conversations about choosing social media groups.
- ➔ Teach appropriate use of online resources.



Potential Changes to Test

DRIVER 5:

Routine emotional and mental health surveillance assessment and screening are part of the clinic and family structure/workflow

Rationale

“Oftentimes within the clinic, there is not enough time to address the emotional side of things that aren’t as easy to measure.”

Physical health issues and needs tend to dictate the flow of a clinic visit. Unless psychosocial assessment surveillance and screening are intentionally built into visit workflows, it is unlikely it will become a routine part of care.

“If you only screen those you think will screen positive, you miss a lot!”

Screening should be carried out in the context of an ongoing conversation with families – a conversation that explains not only the rationale for screening but also lays the foundation for eliciting concerns going forward.²¹

“[Families] need to trust that the provider or practice has their best interest in mind – it’s not about judgement or taking their babies away.”

Appropriate screening should be conducted for all children and families, regardless of how they look or what their perceived needs might be. This universality is particularly important as it helps to alleviate stigma.²¹

Potential Resources and Example Changes To Test

- ➔ Start testing workflow changes for emotional and mental health surveillance and screening on a small scale. AHRQ provides many good tools and resources for establishing clinical protocols and workflows [here](#).
- ➔ Prepare all families for the surveillance and screening process, starting at time of diagnosis:
 - Cincinnati Children’s includes information about the social worker who will see families at their first four visits in their [Information for Families with Babies Newly Diagnosed with Cystic Fibrosis](#). They are also pilot testing [scripts](#) for providers to use in discussing family wellness.
 - ImproveCareNow has developed an [introductory letter and provider scripts](#) for adolescent depression screening.
 - Talking points to introduce mental health screening, and a letter introducing screening, and suggestions for communicating screening scores and referrals have been developed for [type 1 diabetes](#).
- ➔ Practices have successfully integrated American Academy of Pediatrics’ [screening recommendations for teen depression](#) into routine visit workflows, providing one potential model.

Three pediatric subspecialty clinics (for cystic fibrosis, diabetes and inflammatory bowel disease) successfully introduced screening adolescents for depression. Patients completed measures within three minutes without disruption to clinic flow, and they rated the process as easy, comfortable, and valuable.⁶⁰

“Many times, we don’t want to appear to need emotional help because we don’t want to appear to be unable to care for our child...we want to seem to have our act together even though we may only be holding on by a thread.”

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Potential Changes to Test

DRIVER 5: (continued)

Routine emotional and mental health surveillance assessment and screening are part of the clinic and family structure/workflow

Rationale

Considerations for tools

There are a range of assessment tools (some tested more widely than others) to determine the presence and extent of emotional and mental health issues or needs in pediatric patients with chronic conditions and their families. Many of these tools are targeted to a particular population, patient age, and/or clinic setting.

Carefully consider what screening tools work for your population (e.g., age, if proprietary or in the public domain, length, ease of reading for diverse populations) and what recommendations your professional organizations, state Medicaid, and others may provide.

As one resource, the American Academy of Pediatrics' [Mental Health Screening and Assessment Tools for Primary Care](#) provides a listing of mental health screening and assessment tools, summarizing their psychometric testing properties, cultural considerations, costs, and key references.



Real-time feedback and discussion of assessment results are critical for patient and family buy-in

Potential Resources and Example Changes To Test

→ The [Psychosocial Assessment Tool \(PAT\)](#) is a brief parent report screener of psychosocial risk in pediatric health. The PAT allows for identification of a family's areas of risk and resiliency across multiple domains, and provides a determination of family risk based on the total score.



→ [PROMIS](#)[®] (Patient-Reported Outcomes Measurement Information System) is a set of measures that can be used to evaluate and monitor mental and social health in adults and children. Lists of measures can be found [here](#); an article describing development of the PROMIS pediatric stress response items is [here](#)⁶¹.



→ The Patient Health Questionnaire 2-question survey ([PHQ-2](#)) has been validated to screen for depression in adolescents (ages 13+) and adults. The [PHQ-9](#) has been validated for ages 13+ as a follow-up to a positive PHQ-2, and to monitor treatment response. The short versions of the [Moods and Feelings Questionnaire](#) could be considered for younger children.

→ The Cystic Fibrosis Foundation developed clinician [guidelines](#) for screening and treating depression and anxiety in CF patients aged 12 and over and their primary caregivers, with an accompanying [explanation](#) for patients and parents.⁵⁶

→ The [GAD-7](#) is a brief and [valid](#) measure for assessing for generalized anxiety disorder in adults.⁶²

Potential Changes to Test

DRIVER 6:

High quality resources for emotional and mental health are available and accessible

Rationale

“Even in the best of situations, there are very limited mental health resources (psychiatrists, psychologists or therapists in general)”

Assessment and screening must be accompanied by processes to ensure that identified needs are addressed by the right clinical, community, and/or peer resources. Oftentimes, the appropriate resource will not be available within the clinic setting (or the patient’s primary care setting) as psychosocial professionals can be in short supply, so community resources will be needed. However, when possible, referral and follow-up activities should be facilitated by co-located, embedded or local supports such as social workers, care coordinators, and/or parent navigators.²¹

Potential Resources and Example Changes To Test

- ➔ The National Network for Child Psychiatry Access Programs ([NNCPAP](#)) is a clearinghouse of resources for child psychiatry consultation programs across the country, including those that support pediatricians via phone consultation or other “curbside consultations”. Their [network](#) is searchable by state.
- ➔ The Association for Behavioral and Cognitive Therapies provides a [Find a CBT Therapist site](#) for locating a cognitive behavioral therapist.
- ➔ Co-produced by the Psychosocial Professionals group and members of the ICN community, and designed for families and youth living with IBD, the [Finding a Mental Health Provider for Your Child and Teen with IBD](#) toolkit includes information about the importance of addressing mental health needs as part of IBD care, how to find and work with a mental health provider, and what to expect during mental health counseling.
- ➔ Child life specialists can be a source of age-appropriate suggestions to help children cope with stressful experiences like blood draws. The Autism Treatment Network also provides [blood draw toolkits](#) for parents and providers to help prepare children for medical visits and blood draws.



“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 tool box as patients.”



Acknowledgements

This work was funded by a grant from the **American Board of Pediatrics Foundation** (Principal Investigator, Carole Lannon, MD MPH, Senior Quality Advisor, American Board of Pediatrics and Senior Faculty Lead, Learning Networks Program, the Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center) and by a grant from the **Agency for Healthcare Research and Quality** (Award 4R18HS021935-03).

We acknowledge the leadership and support of the American Board of Pediatrics and the American Board of Pediatrics Foundation, specifically, Drs. David Nichols, Virginia Moyer, and Laurel Leslie. We appreciate the vision and encouragement of the American Board of Pediatrics (ABP) Family Leadership Advisory Group (FLAG).

We would like to acknowledge the Learning Networks who contributed ideas and expertise to the development of this initial Change Package:

- **Autism Treatment Network (ATN)/Autism Intervention Research Network on Physical Health (AIR-P)**
- **Cystic Fibrosis Foundation Learning Network (CFLN)**
- **ImproveCareNow (ICN)**
- **Improving Renal Outcomes Collaborative (IROC)**
- **National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC)**
- **Ohio Perinatal Quality Collaborative (OPQC)**
- **Pediatric Rheumatology Care and Outcomes Improvement Network (PR-COIN)**
- **Perinatal Quality Collaborative of North Carolina (PQCNC)**
- **Sickle Cell Treatment and Outcomes Research Network of the Midwest (STORM)**
- **Type 1 Diabetes Exchange (T1D)**



Acknowledgements

We would like to thank the following collaborators for their contributions to this Change Package:

Tom Boat, MD

Tara Bristol-Rouse, ABP FLAG Member

Jennifer Bolden-Pitre, ABP FLAG Member

Laura Bouslaugh, Parent Contributor, PR-COIN

Jennie Briend, Parent Contributor, NPC-QIC

Cheryl L. Brosig-Soto, PhD

George Dellal, Quality Improvement Consultant

Christina DeShaw, Parent Contributor

Diane Eskra, Quality Improvement Consultant

Stephanie Filigno, PhD

Anna Floreen, Parent Contributor, T1D

Jenny Flores, Parent Contributor, IROC

Breck Gamel, Parent Contributor, CFLN

Nancy Griffin, Quality Improvement Consultant

Melvin Heyman, MD

Amy Kelly, Parent Contributor, ALN

Robyn Kinebrew, ABP FLAG Member, Parent Contributor, STORM

Melanie Kohlheim, Parent Contributor, PR-COIN

Adrienne Kovacs, PhD

Amy Kratchman, ABP FLAG Member, Parent Contributor, ALN

Carole Lannon, MD, MPH

Stacey Lihn, ABP FLAG Member, Parent Contributor, NPC-QIC

Laura Mackner, PhD

Laura Miller, Parent Contributor, Perinatal

Elizabeth Moore, Parent Contributor

Sarah Myers, Quality Improvement Consultant

Amy Ohmer, Parent Contributor, T1D

Laura E. Peterson, Quality Improvement Consultant

Diane Pickles, ABP FLAG Member, Parent Contributor, NPC-QIC

Ansara Piebenga, Parent Contributor, IROC

Jill Plevinsky, PhD

Olesya Rockel, Coordinator, Project Management

LaToshia Rouse, Parent Contributor, Perinatal

Kathy Sabadosa, ABP FLAG Member

Tully Saunders, Patient Contributor

Janet Seide, Parent Contributor, ALN

Erica Sood, PhD

Susan Timmins, Parent Contributor

Stephanie Wilson, Senior Specialist, Project Management



References

1. DeMaso DR, Calderon J, Taylor GA, Holland JE, Stopp C, White MT, et al. Psychiatric disorders in adolescents with single ventricle congenital heart disease. *Pediatrics*. 2017 Mar;139(3).
2. Compas BE, Jaser SS, Dunn MJ, Rodriguez EM. Coping with chronic illness in childhood and adolescence. *Annu Rev Clin Psychol*. 2012;8:455–80.
3. Kovacs AH, Moons P. Psychosocial functioning and quality of life in adults with congenital heart disease and heart failure. *Heart Fail Clin*. 2014 Jan;10(1):35–42.
4. 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.
5. Holland JE, Cassidy AR, Stopp C, White MT, Bellinger DC, Rivkin MJ, et al. Psychiatric disorders and function in adolescents with Tetralogy of Fallot. *J Pediatr*. 2017 Aug;187:165–73.
6. Modi AC, Driscoll KA, Montag-Leifling K, Acton JD. Screening for symptoms of depression and anxiety in adolescents and young adults with cystic fibrosis. *Pediatr Pulmonol*. 2011 Feb;46(2):153–9.
7. Marino BS, Cassedy A, Drotar D, Wray J. The impact of neurodevelopmental and psychosocial outcomes on health-related quality of life in survivors of congenital heart disease. *J Pediatr*. 2016 Jul;174:11–22.e2.
8. Secinti E, Thompson E, Richards M, Gaysina D. Research review: childhood chronic physical illness and adult emotional health – a systematic review and meta-analysis. *J Child Psychol Psychiatry*. 2017 Jul;58(7):753–69.
9. Steele AC, Mullins LL, Mullins AJ, Muriel AC. Psychosocial interventions and therapeutic support as a standard of care in pediatric oncology. *Pediatr Blood Cancer*. 2015 Dec;62 Suppl 5:S585-618.
10. Meltzer LJ, Booster GD. Sleep disturbance in caregivers of children with respiratory and atopic disease. *J Pediatr Psychol*. 2016 Jul;41(6):643–50.
11. Woolf-King SE, Anger A, Arnold EA, Weiss SJ, Teitel D. Mental health among parents of children with critical congenital heart defects: a systematic review. *J Am Heart Assoc*. 2017 Feb 1;6(2).
12. Driscoll KA, Montag-Leifling K, Acton JD, Modi AC. Relations between depressive and anxious symptoms and quality of life in caregivers of children with cystic fibrosis. *Pediatr Pulmonol*. 2009 Aug;44(8):784–92.
13. 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.
14. 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.
15. Gerhardt CA, Lehmann V, Long KA, Alderfer MA. Supporting siblings as a standard of care in pediatric oncology. *Pediatr Blood Cancer*. 2015 Dec;62 Suppl 5:S750-804.
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. Boat TF, Filigno S, Amin RS. Wellness for families of children with chronic health disorders. *JAMA Pediatr*. 2017 Sep 1;171(9):825–6.
18. American Board of Medical Specialties [Internet]. [cited 2017 Sep 17]. Available from: <http://www.abms.org/member-boards/contact-an-abms-member-board/american-board-of-pediatrics/>
19. The Chronic Care Model [Internet]. Improving Chronic Illness Care. [cited 2017 Sep 17]. Available from: http://www.improvingchroniccare.org/index.php?p=The_Chronic_Care_Model&s=2



References

20. Kazak AE, Rourke MT, Alderfer MA, Pai A, Reilly AF, Meadows AT. Evidence-based assessment, intervention and psychosocial care in pediatric oncology: a blueprint for comprehensive services across treatment. *J Pediatr Psychol*. 2007 Oct;32(9):1099–110.
21. Radecki L. Needs Assessment – Key Informant Interviews Report. American Academy of Pediatrics; 2016 Sep. (Screening in Practices Initiative).
22. Family Caregiver Alliance National Center on Caregiving [Internet]. [cited 2017 Sep 26]. Available from: <https://www.caregiver.org/taking-care-you-self-care-family-caregivers>
23. Tuning In: Parents of Young Children Speak Up About What They Think, Know and Need. *Zero to Three*; 2016 Jun.
24. Kashikar-Zuck S, Sil S, Lynch-Jordan AM, Ting TV, Peugh J, Schikler KN, et al. Changes in pain coping, catastrophizing, and coping efficacy after cognitive-behavioral therapy in children and adolescents with juvenile fibromyalgia. *J Pain Off J Am Pain Soc*. 2013 May;14(5):492–501.
25. Scholten L, Willems AM, Last BF, Maurice-Stam H, van Dijk EM, Ensink E, et al. Efficacy of psychosocial group intervention for children with chronic illness and their parents. *Pediatrics*. 2013 Apr;131(4):e1196-1203.
26. Thompson RD, Craig A, Crawford EA, Fairclough D, Gonzalez-Heydrich J, Bousvaros A, et al. Longitudinal results of cognitive behavioral treatment for youths with inflammatory bowel disease and depressive symptoms. *J Clin Psychol Med Settings*. 2012 Sep;19(3):329–37.
27. Eccleston C, Fisher E, Law E, Bartlett J, Palermo TM. Psychological interventions for parents of children and adolescents with chronic illness. *Cochrane Database Syst Rev*. 2015 Apr 15;(4):CD009660.
28. Barlow JH, Ellard DR. Psycho-educational interventions for children with chronic disease, parents and siblings: an overview of the research evidence base. *Child Care Health Dev*. 2004 Nov;30(6):637–45.
29. Roberts RM, Ejoava A, Giallo R, Strohm K, Lillie M, Fuss B. A controlled trial of the SibworkS group program for siblings of children with special needs. *Res Dev Disabil*. 2015 Sep;43–44:21–31.
30. Fjorback LO, Arendt M, Ornbøl E, Fink P, Walach H. Mindfulness-based stress reduction and mindfulness-based cognitive therapy: a systematic review of randomized controlled trials. *Acta Psychiatr Scand*. 2011 Aug;124(2):102–19.
31. Marchand WR. Mindfulness-based stress reduction, mindfulness-based cognitive therapy, and Zen meditation for depression, anxiety, pain, and psychological distress. *J Psychiatr Pract*. 2012 Jul;18(4):233–52.
32. Alsubaie M, Abbott R, Dunn B, Dickens C, Keil TF, Henley W, et al. Mechanisms of action in mindfulness-based cognitive therapy (MBCT) and mindfulness-based stress reduction (MBSR) in people with physical and/or psychological conditions: A systematic review. *Clin Psychol Rev*. 2017 Jul;55:74–91.
33. Peer Support in Health and Health Care [Internet]. Peers for Progress: A program of the American Academy of Family Physicians Foundation; 2010 Dec [cited 2017 Sep 26]. Available from: http://peersforprogress.org/wp-content/uploads/2012/07/20120706_pfp_guide_for_pdmgmt_june_2012.pdf
34. Huff M, McClanahan K, Omar H. Chronic Illness and Mental Health Issues. University of Kentucky Pediatrics Faculty Publications; 2010. Report No.: 109.
35. Merianos A, King K, Vidourek R, Nabors L. Mentoring and peer-led interventions to improve quality of life outcomes among adolescents with chronic illnesses. *Appl Res Qual Life*. 2016 Sep;11(3):1009–1023.
36. Shilling V, Morris C, Thompson-Coon J, Ukoumunne O, Rogers M, Logan S. Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies. *Dev Med Child Neurol*. 2013 Jul;55(7):602–9.
37. Hall SL, Ryan DJ, Beatty J, Grubbs L. Recommendations for peer-to-peer support for NICU parents. *J Perinatol Off J Calif Perinat Assoc*. 2015 Dec;35 Suppl 1:S9-13.



References

38. Kingod N, Cleal B, Wahlberg A, Husted GR. Online peer-to-peer communities in the daily lives of people with chronic illness: a qualitative systematic review. *Qual Health Res.* 2017 Jan;27(1):89–99.
39. Allen C, Vassilev I, Kennedy A, Rogers A. Long-term condition self-management support in online communities: a meta-synthesis of qualitative papers. *J Med Internet Res.* 2016 Mar 10;18(3):e61.
40. McEvoy M. An added dimension to the pediatric health maintenance visit: the spiritual history. *J Pediatr Health Care Off Publ Natl Assoc Pediatr Nurse Assoc Pract.* 2000 Oct;14(5):216–20.
41. Reynolds N, Mrug S, Hensler M, Guion K, Madan-Swain A. Spiritual coping and adjustment in adolescents with chronic illness: a 2-year prospective study. *J Pediatr Psychol.* 2014 Jun;39(5):542–51.
42. 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 Pediatr Psychol.* 2014 Sep;39(8):866–86.
43. Feinberg E, Augustyn M, Fitzgerald E, Sandler J, Ferreira-Cesar Suarez Z, Chen N, et al. Improving maternal mental health after a child's diagnosis of autism spectrum disorder: results from a randomized clinical trial. *JAMA Pediatr.* 2014 Jan;168(1):40–6.
44. Bongiovanni TRS, Clark AL, Garnett EA, Wojcicki JM, Heyman MB. Impact of gluten-free camp on quality of life of children and adolescents with celiac disease. *Pediatrics.* 2010 Mar;125(3):e525-529.
45. Salazar G, Heyman MB. Benefits of attending a summer camp for children with inflammatory bowel disease. *J Pediatr Gastroenterol Nutr.* 2014 Jul;59(1):33–8.
46. Moola FJ, Faulkner GEJ, White L, Kirsh JA. The psychological and social impact of camp for children with chronic illnesses: a systematic review update. *Child Care Health Dev.* 2014 Sep;40(5):615–31.
47. Padesky CA, Mooney KA. Strengths-based cognitive-behavioural therapy: a four-step model to build resilience. *Clin Psychol Psychother.* 2012 Aug;19(4):283–90.
48. Hamall KM, Heard TR, Inder KJ, McGill KM, Kay-Lambkin F. The Child Illness and Resilience Program (CHiRP): a study protocol of a stepped care intervention to improve the resilience and wellbeing of families living with childhood chronic illness. *BMC Psychol.* 2014;2(1):5.
49. Bethell C, Gombojav N, Solloway M, Wissow L. Adverse childhood experiences, resilience and mindfulness-based approaches: common denominator issues for children with emotional, mental, or behavioral problems. *Child Adolesc Psychiatr Clin N Am.* 2016 Apr;25(2):139–56.
50. Weitzman, Wegner, the Section on Developmental and Behavioral Pediatrics, Committee on Psychosocial Aspects of Child and Family Health, Council on Early Childhood, and Society for Developmental and Behavioral Pediatrics. Promoting optimal development: screening for behavioral and emotional problems. *Pediatrics.* 2015;135(2):384-395. *Pediatrics.* 2015 May;135(5):946.
51. Lantin-Hermoso MR, Berger S, Bhatt AB, Richerson JE, Morrow R, Freed MD, et al. The care of children with congenital heart disease in their primary medical home. *Pediatrics.* 2017 Nov;140(5).
52. Marino BS, Lipkin PH, Newburger JW, Peacock G, Gerdes M, Gaynor JW, et al. Neurodevelopmental outcomes in children with congenital heart disease: evaluation and management: a scientific statement from the American Heart Association. *Circulation.* 2012 Aug 28;126(9):1143–72.
53. Young-Hyman D, de Groot M, Hill-Briggs F, Gonzalez JS, Hood K, Peyrot M. Psychosocial Care for People With Diabetes: A Position Statement of the American Diabetes Association. *Diabetes Care.* 2016;39(12):2126–40.
54. Kazak AE, Abrams AN, Banks J, Christofferson J, DiDonato S, Grootenhuis MA, et al. Psychosocial assessment as a standard of care in pediatric cancer. *Pediatr Blood Cancer.* 2015 Dec;62 Suppl 5:S426-459.



References

55. Kearney JA, Salley CG, Muriel AC. Standards of psychosocial care for parents of children with cancer. *Pediatr Blood Cancer*. 2015 Dec;62 Suppl 5:S632-683.
56. Quittner AL, Abbott J, Georgiopoulos AM, Goldbeck L, Smith B, Hempstead SE, et al. International Committee on Mental Health in Cystic Fibrosis: Cystic Fibrosis Foundation and European Cystic Fibrosis Society consensus statements for screening and treating depression and anxiety. *Thorax*. 2016 Jan;71(1):26–34.
57. Aquino J. The significance of unknown significance. *Acad Pediatr*. 2017 Dec;17(8):799–800.
58. Center on the Developing Child, Harvard University. Key Concepts: Resilience [Internet]. [cited 2017 Sep 7]. Available from: <https://developingchild.harvard.edu/science/key-concepts/resilience/>
59. Epstein RM, Krasner MS. Physician resilience: what it means, why it matters, and how to promote it. *Acad Med J Assoc Am Med Coll*. 2013 Mar;88(3):301–3.
60. Iturralde E, Adams RN, Barley RC, Bensen R, Christofferson M, Hanes SJ, et al. Implementation of depression screening and global health assessment in pediatric subspecialty clinics. *J Adolesc Health Off Publ Soc Adolesc Med*. 2017 Nov;61(5):591–8.
61. Bevans KB, Gardner W, Pajer K, Riley AW, Forrest CB. Qualitative development of the PROMIS(R) pediatric stress response item banks. *J Pediatr Psychol*. 2013 Mar;38(2):173–91.
62. Spitzer RL, Kroenke K, Williams JBW, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. *Arch Intern Med*. 2006 May 22;166(10):1092–7.

