



# **Addressing Mental Health Outcomes in Children with IBD**

Final Report

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## About the Crohn's and Colitis Foundation

Founded in 1967, the Crohn's and Colitis Foundation (the Foundation)<sup>1</sup> is a non-profit organization dedicated to finding cures for Crohn's disease and ulcerative colitis, and improving the quality of life of those affected by the diseases. The foundation is headquartered in New York City with an additional 40 local chapters throughout the country. Together, these chapters carry out the Foundation's seven main initiatives:

**Research Programs** – The Foundation funds research for a cure and enhanced treatment options. Foundation research has led to breakthroughs in the genetic factors that influence the diseases' onset and progression.

**Education Programs** – The Foundation provides IBD-specific education to the 3.1 million people living with IBD. In addition to online and in-person patient education, the Foundation offers professional education via health professional workshops, continuing medical education modules, and two scientific journals.

**Support Services** – Support services are delivered through local chapters to assist IBD patients in their daily lives. These services include a variety of programming such as support groups, Camp Oasis, and educational workshops.

**Advocacy** – Through multiple legislative initiatives, the Foundation hopes to advocate for those living with IBD and empower IBD patients and their families to advance public policy goals supporting IBD patients.

**Quality of Care** – IBD Qorus seeks to improve the quality of care that IBD patients receive through patient-provider collaboration and co-facilitation of treatment.

**Clinical Trials Community** – The Foundation provides resources to patients interested in participating in clinical trials in order to improve critical drug development processes and increase the variety of treatment options available.

**Fundraising Initiatives** – Through a variety of events, the Foundation fundraises to support its vision of improving the lives of those with IBD. Fundraising takes place year-round across the country in order to support mission critical programming.

Through these initiatives, the Foundation seeks to provide a wealth of resources, basis of support, and brighter future for those suffering from Crohn's disease and ulcerative colitis.

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<sup>1</sup> Adapted from the Foundation's *Mission and Core Values* page <https://www.crohnscolitisfoundation.org/>



## About the Applied Policy Project

The Applied Policy Project (APP) is a policy analysis produced as the capstone of the Master of Public Policy degree at the University of Virginia's Frank Batten School of Leadership and Public Policy. Using the tools and interdisciplinary methods of the Frank Batten School's curriculum, the APP examines a significant public policy question facing an organization in the public, non-profit, or private sectors. This APP was conducted for the Crohn's and Colitis Foundation – Greater Washington D.C. / Virginia Chapter. This project is a culmination of outreach to the Crohn's and Colitis Foundation staff, comparisons to similar organizations working in this issue area, and interviews with relevant stakeholders including children with IBD and their families and pediatric medical practitioners at the UVA hospital. The data collected for this report comes from the Crohn's and Colitis Foundation and an extensive outside literature review.

## Acknowledgements

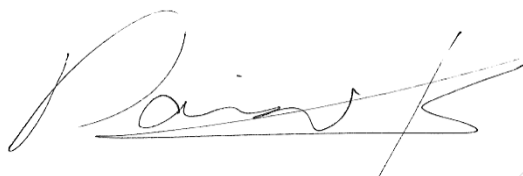
I would like to thank my client, the Crohn's and Colitis Foundation, and particularly Brett Curtis, Development Manager for the Greater Washington D.C. / Virginia Chapter, for your investment and the opportunity to work on this issue.

Lastly, thank you to my colleagues at the Batten School who have been such a formative influence on my education and growth. Thank you to my advisor, Professor Lucy Bassett, for your continued guidance and thoughtful feedback during this process. Thank you to my editing partner, Hannah Gavin, for helping me get to the finish line.

## Disclaimer

The author conducted this study as part of the program of professional education at the Frank Batten School of Leadership and Public Policy, University of Virginia. This paper is submitted in partial fulfillment of the course requirements for the Master of Public Policy degree. The judgments and conclusions are solely those of the author, and are not necessarily endorsed by the Batten School, by the University of Virginia, or by any other agency.

*"On my honor as a student, I have neither given nor received aid on this assignment."*

A handwritten signature in black ink, appearing to read "Raimond", is written over a horizontal line.



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## List of Abbreviations

ACD – adolescent with chronic disease

ADA – American Diabetes Association

CBT – cognitive behavioral therapy

CD – Crohn’s disease

CDI – Child Depression Inventory

CME – continuing medical education

GI doctor – gastroenterologist doctor

GI tract – gastrointestinal tract

HRQoL – health-related quality of life

IBD – inflammatory bowel disease

IC – indeterminate colitis

ICBT – internet-based cognitive behavioral therapy

NVNG program – Nothing Ventured Nothing Gained program

QoL – quality of life

SCAS – C/P – Spence Children’s Anxiety Scale – child and parent version

T1D – Type 1 diabetes

The Foundation – Crohn’s and Colitis Foundation

UC – ulcerative colitis



## Executive Summary

Children with inflammatory bowel disease (IBD) are at an alarming risk for mental health problems. Compared to children in the general population, children with IBD are 1.6 times more likely to have a psychiatric disorder or attempt suicide (Butwicka et al., 2019). These statistics are especially troubling when considering long-term outcomes. Even just having symptoms of depression or anxiety in childhood (without a full-blown diagnosis) can lead to worse mental health outcomes in adulthood (Loftus et al., 2011).

A variety of sociological factors are believed to contribute to these adverse mental health outcomes in children with IBD such as family dynamics, uncertainty about managing the transition to adulthood, and a lack of practitioner engagement. Children with IBD often feel guilty about the stress they put on their family – families with IBD have worse family functioning than families without IBD (Mackner, 2004). Regarding personal development, IBD patients reportedly list establishing autonomy and developing a sense of control as one of their biggest concerns regarding disease management (Mackner, 2004; Mukherjee, 2001). Lastly, IBD patients do not receive preventive mental health services at the same rate as general medical patients since many IBD patients use their gastroenterologist (GI) as their primary care doctor (Farraye, et al., 2017). GI doctors are not trained in mental health services nor possess the proper mental health survey tools to provide adequate mental health care (Szigethy et al., 2017).

In response to this problem, four potential policy alternatives were evaluated:

1. Utilize the Foundation's Existing Online Resources and Support Groups
2. Provide Internet-Based Cognitive Behavioral Therapy (ICBT)
3. Create an Adjunct IBD Call Center for Adolescents
4. Increase Practitioner Engagement through Continuing Medical Education Modules (CME's) and Training Programs

After careful evaluation based on the criteria of cost, effectiveness, feasibility, and children reached, it is recommended the Foundation utilize its existing resources and provide ICBT. Due to Covid-19, online alternatives offer the most cost-efficient means to reach IBD patients. Since many children with IBD are immunocompromised, it is likely they and their families are taking stricter self-isolation measures during this time, which could lead to increased anxiety and depressive symptoms. Providing these online resources would help mitigate the problem by offering immediate relief to IBD patients.



“

I was 12 when I found out I had Crohn's disease. I remember crying my heart out when I heard that there was no cure. The idea of living with something forever terrified me, and it still does. Having Crohn's at such a young age was especially difficult. While other kids were starting to grow, I was shrinking.

”

- *Melanie, diagnosed age 12*



## Introduction

Children's early experiences – the relationships they make with peers, the bonds they form with their parents, the experiences they have at school – have a lasting and profound impact on the adults they will become. While all children will have some type of health problem or illness during infancy or childhood, most of these experiences will be mild, and few will have a lasting impact. However, for some children, these health problems may turn out to be chronic health conditions, such as Crohn's disease or ulcerative colitis, which will affect them every day for the rest of their lives.

While dealing with a chronic health condition can be challenging at any age, children face unique challenges that could significantly alter their social development long into their future (Frankenfield, 2000). Instead of playing outside with friends or worrying about what to wear to homecoming, children with chronic illnesses may be facing frequent doctor and hospital visits, have their activities limited, and in many cases, struggle to connect with their family and friends. Chronic conditions do not only affect physical health, but mental health as well. ***In particular, children with Crohn's disease and ulcerative colitis are 1.6 times more likely to have a psychiatric disorder or attempt suicide*** (Butwicka et al., 2019). It is with this awareness that the Crohn's and Colitis Foundation has chosen to delve into the mental and emotional wellbeing of children with Crohn's disease and ulcerative colitis. The Foundation's mission is to not only find a cure for these diseases but to improve the quality of life of those currently living with these diseases, and nowhere else can we have such a profound impact on another's future than in childhood.

## Background

### *What are Inflammatory Bowel Diseases?*

Inflammatory Bowel Disease (IBD) is an umbrella term used to categorize two primary autoimmune conditions: Crohn's disease and ulcerative colitis (UC). These conditions are characterized by chronic inflammation of the gastrointestinal (GI) tract which manages food, waste, and the absorption of nutrients. Inflammation along the GI tract causes the body to struggle with these processes and can lead to symptoms such as persistent diarrhea, abdominal pain, rectal bleeding, unintended weight loss, fatigue, ulcers, night sweats, and reduced appetite (*see Figure 1*) (CDC, 2018). IBD is also associated with a number of complications that can arise due to disease activity. These complications may include skin, eye, and joint inflammation (including arthritis), irregular periods in females, increased risk for blood clots, bowel obstruction, malnutrition, fistulas, and anal fissures. While IBD itself is not life-threatening, patients are at an increased risk for other life-threatening conditions such as colon cancer and certain cancers caused by the use of strong medications used for treatment (CDC, 2018).

#### Effects on the Body Inflammatory Bowel Disease (IBD)

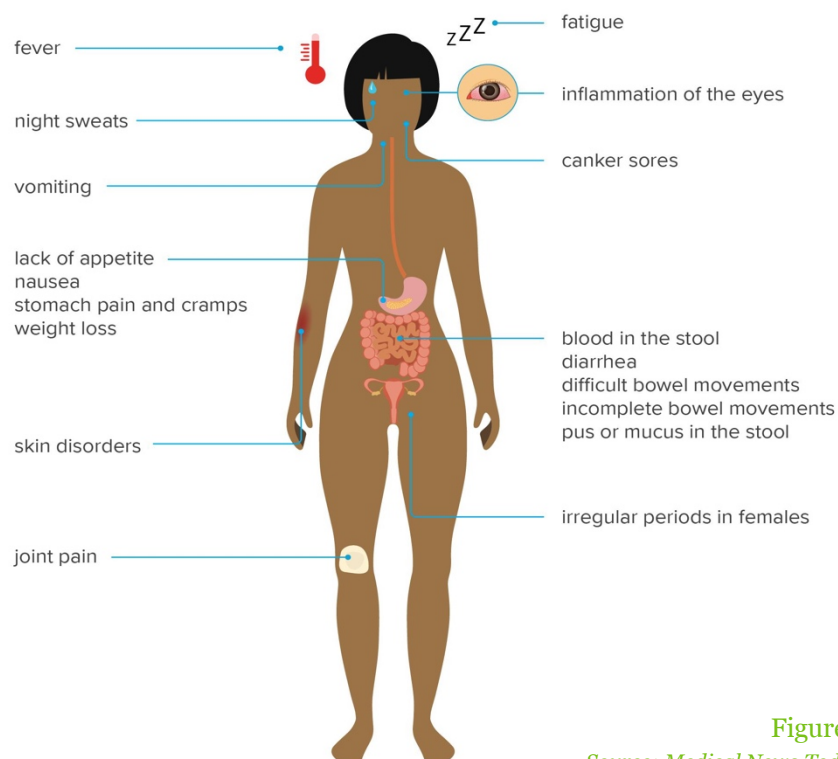


Figure 1

Source: Medical News Today

## Types of Inflammatory Bowel Disease

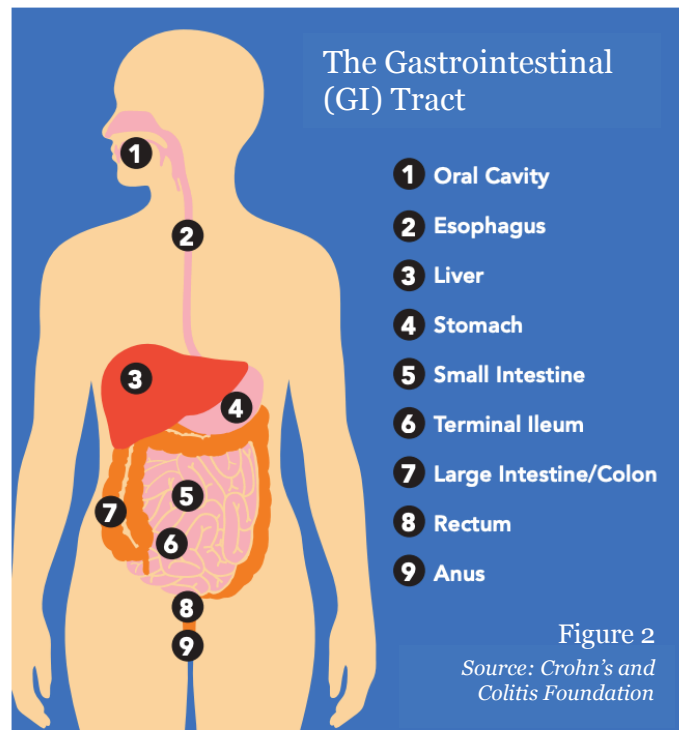
There are three terms used to describe inflammatory bowel disease: Crohn's disease (CD), ulcerative colitis (UC), and indeterminate colitis (IC). Crohn's disease can affect the entire digestive tract from mouth to anus (see 1-9 in *Figure 2*), while UC only inflames the large intestine (see 7 in *Figure 2*). For individuals where it is hard to determine where their IBD has spread, IC is used (Osso, 2017).

## Magnitude and Demographics

Currently, about 3.1 million Americans (1 in every 100) have IBD and as many as 70,000 new diagnoses are made each year (CDC, 2019; Crohn's and Colitis Foundation, 2014). Recent studies have shown that Crohn's disease and UC are becoming more prevalent in children and adults across the United States. It is unclear why this is, but a combination of genetics, environment, diet, and an overactive immune response to bacteria in the gut are believed to be contributing factors (Johns Pool, 2019).

In general, IBD does not differentiate by sex, with men and women being affected equally. However, UC is slightly more common in men than in women. While Crohn's disease and UC can occur at any age, patients are most commonly diagnosed between the ages of 15 and 35 (Crohn's and Colitis Foundation, 2014). Across racial and ethnic groups, IBD is more common in whites than any other group, and Ashkenazi Jews have also reported higher rates of Crohn's disease (Johns Pool, 2019).

Geographically, there are higher rates of IBD in industrialized countries compared to developing nations (Kappelman et al., 2019). It is unclear whether this gap is due to differences in the rates of proper diagnosis or environmental factors. However, in the United States, adults with commercial insurance have a higher prevalence of IBD than adults covered by Medicaid (Kappelman et al., 2019). This suggests that there might be an association between socioeconomic status and IBD. It is possible that low-income groups may be diagnosed less frequently due to a lack of access to medical care. Some researchers have even proposed a "hygiene hypothesis" or the idea that those of higher



socioeconomic status have decreased exposure to infectious agents that could contribute to the development of IBD (Kappelman et al., 2019). New IBD research proposals have focused on finding more definitive answers to these questions.

### ***Inflammatory Bowel Disease in Children***

Of the 3.1 million Americans living with IBD, as many as 80,000 are children or about 10 per every 100,000 (Crohn's and Colitis Foundation, 2014). This accounts for children of pediatric age (<18 years) and represents the fastest growing IBD patient population. In children, slightly more boys than girls develop IBD, and Crohn's disease is twice as common as UC. The reasons for these differences are not yet known, and only recently has research emerged to extensively study IBD in children. However, when IBD is present in children, it is often more extensive and may reach a more severe stage than in adults (Crohn's and Colitis Foundation, 2014). This can cause children with IBD to experience delayed puberty and growth failure. A significant proportion of children with IBD will have final adult heights less than expected due to IBD complications (Crohn's and Colitis Foundation, 2014).

### ***Treatment***

While there are many treatments to help manage IBD and its resulting symptoms, ultimately, Crohn's disease and UC are chronic conditions that cannot be cured. Drug therapy, such as the use of steroids or immunosuppressants, may be considered first to reduce inflammation and suppress the body's natural immune response. Patients may also be encouraged to focus on diet and avoid foods that exacerbate their symptoms. In some cases, patients may even consider enteral feeding (inserting a tube via the nose or directly into the stomach to receive liquid nourishment) or parenteral nutrition (intravenous administration of nutrition) (Mukherjee & Sloper, 2001).

Lastly, surgery may be considered to remove parts of the small or large intestine that are inflamed. Some IBD patients who undergo surgery may be lucky to have their bowel reconnected, but many will be left with an opening in their abdomen (a stoma) which diverts waste into a bag attached to the body (IBD Relief, 2020). Ultimately, about 20 percent of UC patients and 80 percent of Crohn's disease patients will require surgery during their lifetime (Sica & Biancone, 2013). When treatment or surgery manages to suppress inflammation to the point where a patient is no longer experiencing daily symptoms, a period of remission is said to be achieved. Periods of high disease activity where a patient is experiencing symptoms are called "flares." IBD patients often alternate between periods of flares and remission throughout their lives.

## Problem Definition

### Overview

Children (<18 years old) with IBD are at an alarming risk for mental health problems. Compared to children in the general population, children with IBD are 1.6 times more likely to have a psychiatric disorder or attempt suicide. This comparison not only holds between children from the general population but between children with IBD and their siblings without IBD (Butwicka et al., 2019). In particular, children with IBD are 17 percent more likely to be on anti-depressants, and children with Crohn's disease have nearly 3 times the risk of being diagnosed with anxiety or depression (Virta, 2014; Loftus et al., 2011). This risk for depression and anxiety increases within the first year of diagnosis, when children may be 5 times as likely to have one of these disorders due to the struggle of adapting to changing life circumstances (Virta, 2014). These statistics are especially troubling when considering long-term outcomes since psychiatric disorders in childhood and adolescence can often predict worse mental health in adulthood. Even just having symptoms of depression or anxiety in childhood (without a full-blown diagnosis) can predict long-term disorders later in adulthood (Loftus et al., 2011).

### Contributing Factors

IBD can lead to a host of embarrassing symptoms, especially for children who have not yet reached maturity. These symptoms include frequent bathroom use that can amount to 20 trips per day and cause children to become the target of

*“People often asked if I was anorexic because they didn’t know what I was going through. It was like I had a giant secret, and I didn’t want to be asked about it.”*

*– Melanie, diagnosed age 12*

common “bathroom humor” among their peers. This can cause children to avoid talking about their illness for fear of being misunderstood and feel stressed while attending school or going out in public. In addition to embarrassment, children with IBD may feel insecure about their body image due to delayed growth and puberty. Steroids used for treatment can also cause weight gain, especially in the face, and may have additional effects on a child's emotions (Mackner et al., 2004).

Outside of themselves, children with IBD often feel guilty about the stress they put on their family and friends. When children were asked who they were most concerned their condition would affect, they consistently mentioned their family members (Mukherjee,

2004). In fact, IBD does have significant implications for families. Parents and siblings may have to adjust their schedules to accommodate for frequent doctor's visits, hospitalizations, and other medical routines. Due to financial burdens, some parents might not be able to take time off work to care for a child with IBD (*see Figure 3*). Families may also need to make social and dietary sacrifices to accommodate an IBD patient's need for certain types of food or access to restrooms.

As a result of these factors, families with IBD have worse family functioning than families without IBD, and parents with IBD experience more stress and have less energy than parents of children without IBD (Mackner, 2004; Gray et al, 2013). Parental stress can even have a resulting impact on a child with IBD. In more recent studies, parental stress has predicted depressive symptoms of children with IBD (Guilfoyle, 2014). It is not only IBD patients, but their family members, who suffer from adverse mental health outcomes.

Lastly, children with IBD struggle with a lack of control. The disease often takes away a patient's control over physical appearance, energy level, and daily routine. A lack of empowerment is not only a characteristic of IBD, but of most chronic diseases. People with chronic conditions generally struggle with self-management – the ability to manage one's symptoms, treatment, and the life style changes inherent to having a chronic condition (Hooft et al., 2017). IBD patients reportedly list establishing autonomy and developing a sense of control as one of their biggest concerns regarding disease management (Mackner, 2004; Mukherjee, 2001). Without a proper support network to help manage these concerns, children with IBD are often left feeling isolated.

A lack of self-management can also carry on into young adulthood, especially when adolescents begin the transition to further education or the workforce. The added complexities of managing a chronic illness during this time period can prove overwhelming for many adolescents with IBD. While most teens look forward to this

### ***The Financial Burden of IBD***

**The healthcare costs of people with IBD are 3x that of people without IBD**

**Average healthcare costs the first year after diagnosis are \$26,000**

**The average annual cost of Crohn's disease is between \$8,265 - \$18,963**

**The average annual cost of UC is between \$5,066 - \$15,020**

**Total annual costs to all IBD patients in the US range from \$11 billion to \$28 billion**

Figure 3

Source: Crohn's and Colitis Foundation, 2014; Johns Pool, 2019



transition, children with IBD face a series of new challenges including taking over their own medical care regiment and considering how and whether their disease will permit them to manage the transition to college or the workforce. Children with IBD may face several limitations when considering colleges that involve their access to treatment, health insurance, transition to adult-oriented care, and the ability to handle common stressors of college life. Because of these factors, children with IBD struggle to make the college transition more than healthy children (Almadani et al., 2014; Pham et al., 2019). Regardless of having a chronic illness, half of college students struggle with health insurance literacy and do not fully understand their health insurance plan. About 25 percent of college students even delay medical care due to these confusions (Nobles et al., 2018). In children with IBD specifically (>10 years), only 47 percent possess the health literacy necessary for transition to adult care (Huang et al. 2012). The inability to navigate this transition period can severely exacerbate anxiousness about the future in children with IBD and contribute to a further sense of a loss of control.

### ***Barriers to Treatment***

One of the most significant contributing factors to the adverse mental health outcomes in IBD patients is the reality that IBD patients do not receive preventive mental health services at the same rate as general medical patients (Farraye, et al., 2017). This is partly because many IBD patients use their gastroenterologist (GI) as their main doctor. Since IBD patients visit their GIs frequently (every 6 months during periods of remission and more frequently during flares), they often do not visit a primary care doctor. For children especially, it can be traumatic to attend yet another doctor's appointment. However, a GI doctor's main focus is on choosing the appropriate therapy to achieve remission. Mental health screening is usually handled by primary care doctors, and GI doctors are not trained in mental health services nor possess the proper mental health survey tools or behavioral health resources to deliver adequate mental health care (Szigethy et al., 2017). This means that IBD patients often lose an opportunity to receive preventive screening (Farraye et al., 2017, Szigethy et al., 2017). One study found that GI practitioners failed to even ask about mental health or a patient's wellbeing. Out of over 750 patients, only 15 percent of respondents were asked about their mental health by their GI practitioner although 65 percent reported they would have liked to have been asked (Mikocka-Walus et al., 2019).

Even if GI doctors are aware of the increased risk of mental health problems in children with IBD and possess necessary screening tools, they might still lack the appropriate resources for patient follow-up. GI practitioners might not be aware of mental health providers specializing in IBD and feel pressure to refer patients who screen positive for



mental health issues in a timely manner (Szigethy et al., 2017). This may cause GI practitioners to fear liability issues, especially for patients who express suicidal thoughts on a mental health screening, and avoid screening patients altogether to circumvent the issue (Szigethy et al., 2017). Taken together, it is unlikely IBD patients will receive screenings or a resulting access to mental health care providers unless they visit their primary care doctor or advocate for themselves.

## Best Practices

A review of the literature regarding best practices to address the problem follows below.

### *Cognitive Behavioral Therapy*

One form of treatment that has been used to address stress and anxiety in children with chronic diseases is cognitive behavioral therapy (CBT). CBT is a type of talk therapy (psychotherapy) which involves working with a therapist to become aware of negative thinking in order to develop responses to challenging situations (Mayo Clinic, 2019). CBT often focuses on the importance of appraisal – the idea that a situation cannot be deemed stressful unless the affected individual chooses to appraise it as stressful. In the process of appraisal, stressors are initially assessed by individuals to decide whether they threaten one's goals, sense of self, or situational intention. If the situation does not threaten these objectives, the individual can disregard the potential stressor. If the stressor is deemed to affect these components, an individual then assesses their ability to deal with the stressor. This includes evaluating the situation as a challenge or threat. Based off this assessment, an individual can then develop a course of action for how to handle the situation. For situations deemed challenges, action may include using material or physical resources to cope. For situations deemed threats, action may include using learned coping strategies to handle emotions (Mukherjee et al., 2001).

#### **CBT Based Approach: Case Example**

The model in *Figure 4* can be applied to a situation involving a child who is dealing with increased absenteeism from school due to disease symptoms. Missing school can be stressful for a child since they may fall behind in classes and miss out on social opportunities with friends. A child will likely appraise this situation as threatening or challenging because it hurts their sense of self and goals for learning. If support is available in the form of resources such as at-home tutors, parents, a mental health practitioner, or friends who visit after school, then a child may view the situation as a challenge and mobilize these resources to best cope with the situation. However, if this support is not readily accessible, the child will more likely view the situation as a threat. A child may then go through learned coping mechanisms that include reducing negative emotions and re-evaluating what can be done with limited resources. If a child can successfully mobilize coping resources or strategies, then a positive outcome is achieved. If a child's coping resources are severely limited and coping strategies are unsuccessful, a negative outcome is likely to pursue alongside feelings of distress. Using a CBT approach allows a child to avoid negative outcomes by both enhancing their coping resources and strategies over time.

# CBT Based Approach

## Primary Appraisal

Is the situation significant to my wellbeing?

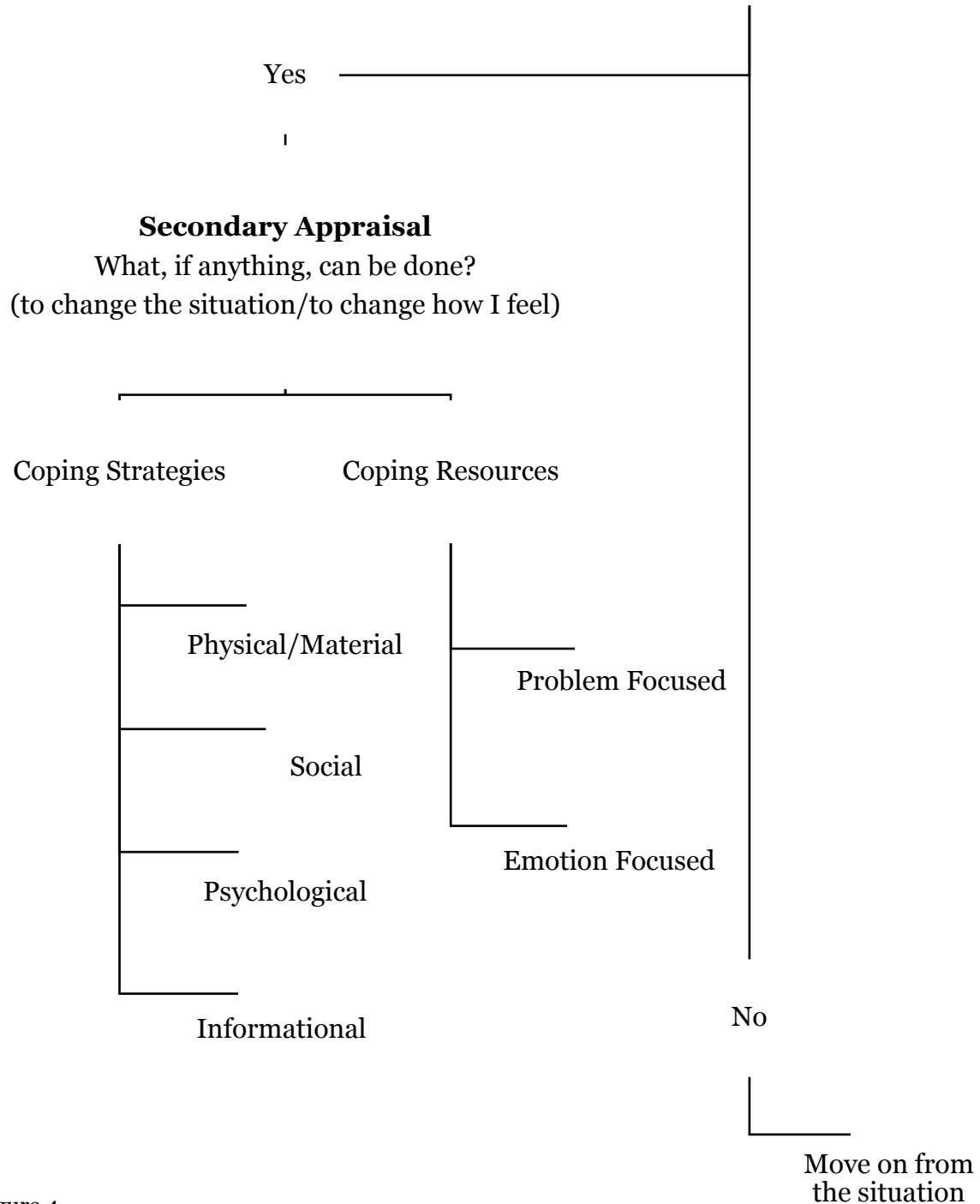


Figure 4  
Adapted from Mukherjee, 2011

Some studies have shown that CBT can mitigate existing IBD symptoms in adult and adolescent IBD patients and lessen long-term mental health complications (Szigethy, 2007; Karwowski et al., 2009). The “coping resources” form of CBT (exemplified in *Figure 4*) was found especially helpful for IBD patients with anxiety. In one study (ages 11-17), 88 percent of treatment completers had some form of reduced anxiety symptoms (Reigada et al., 2013). However, some of these CBT treatments were given by telephone to allow for greater retention in the study and increase treatment flexibility. While telephone sessions such as these have proven to be helpful in increasing treatment accessibility for children with IBD, many insurance companies will not cover the cost of CBT sessions delivered via telephone or internet (Reigada et al., 2013). Without appropriate coverage, these therapies remain inaccessible to certain patients until further research on virtual sessions can convince insurance companies to expand their coverage. In addition, some of the results from these studies are not statistically significant since they use small sample sizes, poor randomization, and different psychotherapeutic methods (individual vs. group therapy) (Prasko et al., 2010). However, CBT has been studied in children with other chronic illnesses such as diabetes, lupus, fibromyalgia, and cancer. These studies have replicated the results found in children with IBD and ultimately reduced depressive symptoms and anxiety in children with chronic conditions (Kazak, 2005; Sil & Kashikar-Zuck, 2013; McGrady & Hood, 2013; Liang et al., 2014; Knight et al., 2016; Cunningham et al., 2019).

### ***Family-Based Interventions***

As previously mentioned, IBD impacts entire families and compounded stress among all family members can worsen the stress of a child with IBD. This is consistent with the “family systems-illness model” which states that illness creates stress to the entire family, not just the individual affected by the illness (Mukherjee, 2001). According to the model, the uncertainty of illness causes a family to fluctuate between crisis and non-crisis moments. During these fluctuations, communication breaks down and family relationships become strained. Families who respond poorly and have a breakdown in overall family-functioning have worse health outcomes than families who maintain strong family-functioning (Mukherjee, 2001). In one study that examined 80 children with IBD between the ages of 7-18, those with well-functioning family measures were more likely to be open with their feelings and express negative feelings such as anxiousness, depression, anger, and despair. This allowed children to get their feelings off their chest and feel closer to family members. Those with a “closed-off” family environment did not experience the same benefits (Engstrom, 1999). However, some of the results from the study were hard to gather and insignificant since children often gave short responses that lacked emotional depth.

Despite the limitations of the IBD study, the importance of a family systems-based approach to improve quality of life (QoL) outcomes has been replicated in other studies. In a study that examined a family teamwork intervention in children aged 8-17 years old with Type 1 diabetes (T1D) (see *Appendix A* for a case study of the *Nothing Ventured Nothing Gained* program), education on diabetes health management and skills training for communication between family members was provided to patients. The intervention was found to improve the wellbeing of the children with T1D and their parents (Hilliard et al., 2016). This is significant because similar to IBD, parents of children with T1D also have worse psychological health than parents with healthy children. In T1D, worse parental mental health also has potential adverse effects on the mental wellbeing of a child with T1D (Helgeson et al., 2012). Similar results have been reported in families of children with cancer, where reported adolescent distress has similarly been tied to parental distress (Kearney et al., 2016; Peikert et al., 2018). These findings point to the importance of family-based interventions.

### ***Self-Management Interventions***

Self-management involves the extent of a patient's ownership over the responsibilities in managing their own care. These responsibilities can include medical management, making lifestyle changes to adjust to disease demands, and managing the emotional impact of having a chronic condition (Crohn's and Colitis Foundation, 2019). For children with IBD specifically, this can involve attending/scheduling medical appointments, taking prescribed medication, diet choices, and symptom management. In addition to these typical medical responsibilities, children with IBD must also manage how their disease interacts with academic studies and learn how to develop social relationships with their peers. Poor self-management can also worsen a child's mental health and increase treatment nonadherence, which can then worsen physical health (Crohn's and Colitis Foundation, 2019). On the other hand, taking individual ownership of one's healthcare processes has been associated with improved health and general QoL outcomes for IBD patients (Plevinsky et al., 2016). Self-management interventions can help individuals regain their sense of control and manage the related stressors that come with adhering to intensive medical treatment and managing the logistical components of healthcare (such as scheduling appointments and coordinating care between multiple doctors/insurance providers).

In a general study of adults with chronic conditions, the most effective forms of self-management interventions focused on self-efficacy and intrinsic processes. These strategies included in-person education about managing daily disease-related problems

via telephone calls, brochures, or group sessions. Patients also learned “how-to”-skills such as breathing techniques aimed at relaxation, best practices for consuming alcohol and smoking, and setting goals for daily exercise. Reflecting on disease management failures and filling out a related worksheet to improve management in the future also proved effective (Hooft et al., 2017). In a study of over 700 adults with IBD, self-management interventions similarly targeting patient healthcare education decreased doctor’s visits and improved overall QoL (Kennedy et al., 2004; Karwowski et al., 2009).

Based off of these interventions, several new studies have attempted to replicate these results through online interventions in adults. In Denmark and Ireland, over 300 UC patients were randomized to receive either usual care along with disease specific education and self-treatment options via a website or just usual care over the course of a year. Patients who were assigned to the web-group had shorter periods of relapse, fewer routine doctor’s visits, and improved overall QoL scores (Elkjaer et al., 2010). In another study, over 80 adolescents with chronic disease (ACD) aged 12-20 were randomized to receive an online and text-delivered disease management intervention. Those in the treatment group received materials on general health topics and tailored disease management tips. After eight months, ACDs in the treatment group had improved performance of disease management tasks and feelings of self-efficacy (Huang et al., 2014). Although no studies have substantially reviewed self-management interventions in children, the results for adults are promising. As a result, the Foundation has designated self-management interventions in children a top research priority (Crohn’s and Colitis Foundation, 2019).

### ***Practitioner Engagement***

There are many studies that point to the effectiveness of practitioner engagement as a preventive measure to avoid mental illness in children with IBD (Smith et al., 2002; Engelmann et al., 2015; Farraye et al., 2017). In addition, due to several population risk factors (having a chronic disease, facing increased stress, etc.), IBD patients are believed to benefit from more intensive mental health screening by practitioners (Farraye et al., 2017; Byrne, 2018). The downside of screening is that it is a single interaction. Certain situations may require stronger interventions or repeated engagement with practitioners. Some patients who may be hospitalized for an extended period of time could benefit more from practitioners who interact with them frequently.

There are some studies that have advocated for nurse led counseling. It is believed that nurses are well placed to help patients accept and understand their illness (Smith et al., 2002). In one study, nurses provided patients with educational videos describing life

with IBD and pamphlets on symptoms, drugs, diet, treatment options, and mental health resources (Smith et al., 2002). Patients were also encouraged to join support groups. Mental health in this study was measured by a health-related quality of life (HRQoL) index. HRQoL can be defined as “an individual's perception of their position in life in the context of the culture and value systems in which they live in relation to their goals, expectations, standards and concerns” (Karwowski et al., 2009). Patients who received this treatment reported a higher HRQoL than those who did not receive the additional support (Smith et al., 2017). Although promising, the study showed that counseling only improved outcomes in the initial 6 months of treatment, and both treatment groups returned to the same quality of life after 12 months (Smith et al., 2017). Nurse led counseling may meet immediate needs, but longer interventions may still be needed to handle this lifelong condition.

## Evaluative Criteria

In response to the defined problem, four potential courses of action are proposed for the Foundation to implement. Each alternative will be assessed using the Pugh method – a decision making model used to evaluate alternatives against a baseline (Hessing, 2014). The Foundation’s status quo will be assigned a baseline score according to a set of criteria. Each additional alternative will receive the same evaluation and then be compared to the baseline. The baseline is represented by a score of zero. Alternatives may score equal to (0), better than (+1), much better than (+2), worse than (-1), or much worse than (-2) the baseline (see Figure 5). After each alternative has been evaluated, overall results will be projected in an outcomes matrix.

### Criteria Scoring Model

Score	Meaning
+2	Much better than
+1	Better than
0	Equal to*
-1	Worse than
-2	Much worse than

*\*Relative to the baseline*

Figure 5

### ***Cost – Does this alternative align with the Foundation’s budget constraints? (Weighted 2x)***

Due to Covid-19, the Foundation has had to cancel or postpone nearly all in-person spring fundraising events. Fundraising events for the summer are currently pending based on how the pandemic evolves over the next couple of months. Similarly, many regular donors to the Foundation have had their financial circumstances altered by the crisis and are contributing less. This means the Foundation is currently operating on a restricted budget and in a state of mission critical funding. As a result, cost will be weighted two times that of the other criteria (which are all weighted equally).

This criterion will be measured by determining any possible costs that may result from alternative implementation. These costs may include but are not limited to additional staff personnel, development costs, and continuing operating costs. Costs will be assessed using the Foundation’s 2019 budgetary data and average market prices.



Alternatives which receive a score of 0 will have a total cost close to, if not equal to, the baseline. Alternatives scoring +2 will cost at least two times less than the baseline. Alternatives scoring +1 will cost less than the baseline. Alternatives scoring -1 will cost more than the baseline. Alternatives scoring -2 will cost at least twice as much as the baseline.

### Cost Scoring Model

Score	Meaning
+2	>2x less cost
+1	Lesser cost
0	Equal to*
-1	Higher cost
-2	>2x higher cost

*\*Relative to the baseline*

### **Effectiveness – Is there significant evidence supporting the alternative?**

Given the Foundation’s mission to improve the quality of life of children affected by these diseases, effectiveness will be measured by how much an alternative improves a patient’s quality of life. This will be measured by surveying the literature surrounding the methods proposed in each alternative. Alternatives that propose methods that have been proven to have a large effect size on the mental wellbeing of children will receive higher scores. Studies that use scientific measures of mental wellbeing such as HRQoL, Spence Children’s Anxiety Scale - child and parent version (SCAS-C/P), and Child Depression Inventory (CDI) will be considered. For a further explanation and examination of these measurement techniques, see *Appendix B*. The magnitude of effect size will be categorized based off of best practices – 0.2 small, 0.5 medium, 0.8 large (McLeod, 2019). In addition to the magnitude of effect size, reliability will also be considered as a subcategory. Methods will not be considered maximally effective unless there are multiple studies verifying the supposed effect. Studies should also have a variety of sample sizes that can prove significant results.

At this time, the Foundation’s status quo has not been evaluated. This means that there is no evidence supporting the effectiveness of the baseline. As a result, 0 will mark the baseline and methods without evaluated effectiveness will score likewise. Alternatives that propose methods with a positive (meaning improved QoL), small - large effect size will score +1. Alternatives that propose methods with a positive, medium - large effect

size and show reliability will score +2. Alternatives that propose methods with negative (meaning worsened QoL), small - large effects will score -1. Alternatives that propose methods with negative, medium – large effects and reliable data will score -2.

### Effectiveness Scoring Model

Score	Meaning
+2	Significant positive effect and reliable
+1	Significant positive effect
0	Equal to*
-1	Significant negative effect
-2	Significant negative effect and reliable

*\*Relative to the baseline*

### Feasibility – How possible is it to implement the alternative?

Due to the Foundation’s status as a non-profit and Covid-19, staff and resources are limited. As a result, feasibility will measure how easily the Foundation can implement each alternative given its existing resources and administrative context. Feasibility will be measured from a qualitative standpoint based on the following factors:

- Is there existing infrastructure (i.e. staff, technical components, other resources) to help implement the option? (Yes/No)
- Are Foundation employees likely to cooperate in administering the alternative? (Yes/No)
- Is there a precedent that the Foundation can model the alternative after? (Yes/No)
- Does the alternative support the Foundation’s overall mission statement and priorities? (Yes/No)

Alternatives will score better if each question can be answered “yes.” Alternatives that respond “yes” to one question more than the baseline will score +1. Alternatives that respond “yes” to two or more questions than the baseline will score +2. Alternatives that respond “no” to one more question than the baseline will score -1. Alternatives that respond “no” to two or more questions than the baseline will score -2.

## Feasibility Scoring Model

Score	Meaning
+2	2 more feasibility measures than the baseline
+1	1 more feasibility measure than the baseline
0	Equal to*
-1	1 less feasibility measure than the baseline
-2	2 less feasibility measures than the baseline

*\*Relative to the baseline*

### ***Children Reached – How many children will this alternative reach?***

Children reached will be measured by the uptake number for each alternative. In addition, the age range of children accessing each alternative will also be considered. Data regarding the Foundation's current patient and practitioner base will be used to estimate how many children an alternative may reach. In addition to raw numbers, alternatives will be assessed by the age range of children targeted. Alternatives that target children of all ages will receive higher scores than alternatives that only target a specific age range. Alternatives that reach more children than the baseline from a numbers or age range standpoint will receive a score of +1. Alternatives that reach more children from a numbers and age range standpoint will receive a score of +2. Alternatives that reach fewer children than the baseline from a numbers or age range standpoint will receive a score of -1. Alternatives that reach fewer children than the baseline from a numbers and age range standpoint will receive a score of -2. Alternatives that match the baseline from a numbers and age range standpoint will receive a 0.

## Children Reached Scoring Model

Score	Meaning
+2	More children reached in numbers and age
+1	More children reached in numbers or age
0	Equal to*
-1	Fewer children reached in numbers or age
-2	Fewer children reached in numbers and age

*\*Relative to the baseline*

## Alternatives

In this section, four potential courses of action for the Foundation to address adverse mental health outcomes in children with IBD are described. Each alternative is evaluated according to the criteria described in the previous section.

### *Status Quo: Utilize Existing Online Resources and Support Groups*

**Overall Score (Baseline) – (0 pts)**

Allowing present trends to continue, the Foundation will maintain a “Mental Health” page on their website that provides a general overview of emotional wellbeing and tips for managing IBD related mental health issues. These tips include general coping strategies, written instructions on progressive muscle relaxation and diaphragmatic breathing, and a “Resources and References” page which includes a nationwide list of mental health providers with experience in psychology and gastroenterology (see *Appendix C* for images of these webpages) .

There are also links to virtual and in-person support groups that either a patient or caregiver may attend. The Foundation currently has about 30 active in-person support groups for children, teens, or caregivers of children. Some states, such as North Dakota, Arkansas, West Virginia, Wyoming, and Alaska do not have in-person support groups at all. Although some of these states do not have local chapters, support groups are not dependent on having a local chapter within the state. Some states without local chapters still have a significant amount of support groups since support groups are dependent on volunteer coordination, contact with the Foundation, and demand within a given area. In-person support groups are for patients and caregivers to share stories, seek emotional support, ask questions, and connect with fellow IBD community members. Support groups may also host informal social events such as picnics, luncheons, volunteer days, and other family outings. Both in-person and online support groups are led by a Foundation volunteer who has been trained as a moderator.

Online support groups are offered in a reoccurring monthly series with sessions for either patients or caregivers. In these 4-week sessions, patients or caregivers participate in weekly chat sessions that cover specific topics regarding living or caring for someone with Crohn’s disease or UC. Patients and caregivers are encouraged to attend all four sessions in order to build community over the four weeks. However, patients may

register at any point during the four weeks until participation is capped at 35 participants (see *Appendix D* for a detailed description of existing online support group session topics).

This option takes immediate action to address the problem since a patient may access these resources at any time and reach out to their local support group through a coordinator listed online. While overall management of disease symptoms can affect mental wellbeing, this alternative does not include an initiative or platform purely dedicated to mental wellbeing. This status quo would remain for the near future since there are no current plans to launch an initiative focusing on mental health in children.

### **Cost – (0 pts)**

The cost of maintaining these existing resources and support groups is generally low. Foundation virtual and in-person support groups are currently led by volunteers whose work hours are free. The primary costs of maintaining the Foundation's existing resources come from regular website maintenance. The Foundation currently contracts its website maintenance out to IT technicians. The Foundation's 2019 hourly IT technician rate was \$175. Website maintenance includes weekly backups, monthly plugin and security updates, biannual performance checks, and year-end evaluations (Teson, 2018). Based on average market rates, this amounts to about \$450 per month or \$5,400 per year in expenditures (WebFX, 2020). Current Foundation staff members update the support group pages and other online resource materials as part of their existing duties, so no additional staff personnel would be needed.

### **Effectiveness – (0 pts)**

Social support from other adolescents and patients with IBD has been proven to have a positive effect on an adolescent's ability to cope with IBD (Karwowski et al, 2009). While this research is both substantially and statistically significant, the Foundation has not yet evaluated its own support groups or mental health offerings. In addition, the support groups offered are not uniform in topic or age range, and some local chapters have more types of support groups than others. For the most part, in-person and online support groups cover general topics about the disease without a specific focus on the mental health issues prevalent in patients with IBD.

It is especially unclear what the effect of the Foundation's support groups are on children or whether children access these support groups with a parent or by themselves. In addition, the Foundation has not evaluated its existing mental health resources on its website. To properly assess the Foundation's existing resources, patient feedback on existing support groups and website materials is needed.

### Feasibility – (0 pts)

To create a baseline for this criterion, the Foundation's existing resources were evaluated against the questions determining feasibility. Overall, the baseline answered "yes" to three feasibility questions. Additional alternatives will be compared to this score.

Is there existing infrastructure (i.e. staff, technical components, other resources) to help implement the option?

- **Yes**, existing web resources and support groups are in-place or uploaded and would not need to be altered.

Are Foundation employees likely to cooperate in administering the alternative?

- **Yes**, there has been no pushback from employees regarding the existing materials and resources.

Is there a precedent that the Foundation can model the alternative after?

- **Yes**, the precedent is the resources the Foundation already provides through its online website.

Does the alternative support the Foundation's overall mission statement and priorities?

- **No**, the Foundation's mission is to provide programming to improve the quality of life of those living with IBD. By leaving out comprehensive mental health programming, the Foundation is ignoring a significant factor that affects the quality of life of IBD patients. In addition, the Foundation has recognized the risk of adverse mental health outcomes for adults and children with IBD and designated the issue as a priority but has yet to develop substantial programming.

### Children Reached – (0 pts)

#### *Uptake*

Last year, 9,123 patients and caregivers accessed the Foundation's online or in person support groups. While it is unclear how many children with IBD have access to the Foundation's website, children represent about five percent of the IBD population (Crohn's and Colitis Foundation, 2019). Out of the current number of patients and caregivers who access the Foundation's support groups, about 456 can be assumed to be children or representative of children. Additionally, the Foundation reportedly reached over 250,000 online users through various online support programs and resources in 2018 (Crohn's and Colitis Foundation, 2019). Using the five percent of patients and caregivers who represent children, it can be assumed about 12,500 total users (including the 9,123 support group users) accessed the Foundation's existing support resources.

*\*Additional Note – Due to Covid-19, the Foundation’s website traffic and downloads of education materials has increased five-fold – potentially increasing the number of people reached to 62,500 children and their caregivers during this time.*

#### *Age Range*

Since the Foundation’s website and support groups are open to patients of all ages and caregivers, this option targets children of all ages. However, of the Foundation’s existing in-person support groups, only about 11 are open to children of all ages. About 12 are open to teens, and about 7 are open to caregivers of children with IBD.

## ***Provide Internet-Based Cognitive Behavioral Therapy (ICBT)***

### **Overall Score – (0 pts)**

While the Foundation currently has an online platform for a reoccurring virtual support series, none of these sessions focus entirely on mental health, let alone mental health in children. The Foundation could launch a reoccurring “Cognitive Behavioral Therapy for Children” series on its website to increase user access to mental health resources. The series would be based off of the Foundation’s current format for online support groups and include separate options for both children and caregivers. A trained volunteer in CBT could lead group sessions focused on developing relaxation and cognitive restructuring techniques in the context of IBD-specific situations. For example, CBT might target fears related to situations involving IBD pain or anxiety and then shape cognitive responses around addressing these triggers (Reigada et al., 2013). In addition to having moderators lead sessions, individual, user-led sessions could also be considered. An existing model for a user-led child and parent online CBT program exists through BRAVE-ONLINE – a platform created by University of Queensland researchers that provides evidence-based CBT sessions for children aged 8-17. BRAVE sessions deliver content through animated educational materials, quizzes, puzzles, and games (The Brave Program, 2020).

The provision of separate sessions for both patients and caregivers is encouraged based on the family-systems model and supporting evidence that parental mental wellbeing is tied to a child’s mental outcomes (Mackner, 2004; Gray et al, 2013; Hilliard et al., 2016; Kearney et al., 2016; Peikert et al., 2018). In addition, the series for children would ideally target children between the ages of 8-18. CBT has not been extensively studied in children younger than 8 years old, who would require special modifications for easier usability (Minde et al., 2010). Hopefully, having this resource online would provide the most accessibility to all IBD patients and remove some of the financial barriers associated with virtual CBT since most insurance companies do not cover virtual therapy.

### **Cost – Higher Cost (-1 pts) x 2 = (-2 pts)**

The cost of providing an additional virtual support group for children is relatively low. Since support group and general physician hours to the Foundation are volunteered, bringing in a psychologist to lead these sessions would not cost anything. The Foundation currently has a variety of physician volunteers, some of whom are certified in providing CBT to children. Website maintenance costs for these groups would be included in the Foundation’s existing budget (\$5,400 annually). However, there would



be a start-up cost to build out an additional ICBT webpage and home-page announcement. These additional costs are estimated at about \$525 (3 hours of work to build additional webpage on existing platform). While this option would not require additional staff personnel, the Foundation's support programs manager would incur costs associated with developing and coordinating the new ICBT content. The median salary in the United States is \$56,516 which amounts to an hourly wage of about \$27 (US Census Bureau, 2016). Assuming 40 hours spent on program development, the Foundation would incur another \$1,080 in labor costs. All things considered, this option would cost about \$7,005 (including baseline costs).

### **Effectiveness – Significant Positive Effect and Reliable ( +2 pts)**

Since these sessions would be based on research that has evaluated mental health in children with IBD specifically, they would be more effective than the Foundation's general virtual support groups and existing online mental health resources. However, it is also important to consider that the majority of studies evaluating CBT in children with IBD were done in person, not online. To take this into account, additional studies evaluating CBT in children through virtual sessions were also considered. Based on existing research, ICBT is reliable and statistically significant, with all studies reporting small – large effect sizes (>0.2 effect size) (March et al., 2009; Vigerland et al., 2016; Jolstedt et al., 2017; Lalouni et al., 2019; Stjerneklar, 2019).

### **Feasibility – Better Than the Baseline (+1 pts)**

Feasibility is evaluated against the baseline according to the following questions. This alternative answered “yes” to four questions – a one question improvement over the baseline.

Is there existing infrastructure (i.e. staff, technical components, other resources) to help implement the option?

- **Yes**, ICBT can be delivered through the Foundation's existing online platform for virtual support groups.

Are Foundation employees likely to cooperate in administering the alternative?

- **Yes**, it is likely the Foundation administration would back this initiative given there is an existing platform for delivery and liability concerns can be assuaged by the strong evidence supporting ICBT.

Is there a precedent that the Foundation can model the alternative after?

- **Yes**, the Foundation can model ICBT based off of its existing online virtual support groups or the BRAVE program.

Does the alternative support the Foundation's overall mission statement and priorities?

- **Yes**, addressing the mental wellbeing of children with IBD directly coincides with improving the overall quality of life of children with IBD without taking away resources from other patients.

### **Children Reached – Fewer Children Reached in Numbers (-1 pts)**

#### *Uptake*

Using the logic and numbers established from the baseline, it is assumed about 456 children or caregivers of children will access ICBT (Crohn's and Colitis Foundation, 2019). This uptake number is smaller than the baseline's uptake number of 12,500.

#### *Age Range*

Due to research and user-ability issues, the ICBT series for children would only reach those between the ages of 8-18. However, the caregiver series would reach all caregivers regardless of patient age, meaning all age groups could potentially be affected. As a result, the same age ranges are reached comparative to the baseline.

*\*Additional Note – Due to Covid-19, the Foundation's website traffic has increased five-fold, meaning it is likely more children and their caregivers will access online ICBT at this time.*

## Create an Adjunct IBD Call Center for Adolescents

### Overall Score – ( -5 pts)

Currently, the Foundation operates an IBD Help Center that has specialists available Monday through Friday from 9 a.m. to 5 p.m. The call center assists patients who have questions about Crohn's disease or ulcerative colitis. Specialists can also point patients toward specific resources, refer patients to other organizations, and assist with understanding certain insurance coverage details. Lastly, the call center provides informational brochures on a variety of health-related topics.

The Foundation can expand its existing call center to include call lines geared toward adolescents (14-18). These call lines could provide similar services to the main call center but offer advice and resources focused on youth self-management interventions and the transition to adult care. Call lines centered around adolescents could compile mental health literacy materials and resources especially geared toward college or workforce-bound students. Mental health literacy materials for adolescents could be based off of the *Nothing Ventured Nothing Gained* program (see *Appendix A*). Resources for adolescents transitioning to adulthood could include a database of IBD-specific practitioners and resources (medicine infusion centers, local food stores, local support networks) around college universities, how to request academic accommodations, health insurance literacy materials, text-reminder programs for upcoming medical appointments, and tips for eventually transitioning from pediatric to adult care. In talking with high school Foundation patients, the future transition to adulthood and self-managed care repeatedly came up as an anxiety inducing concern (Schraml, 2020; Wardlaw, 2020). Adolescent patients could benefit from a resource lifeline as they grow older and take on more responsibility in their disease management.

### Cost – Greater than 2x the Cost of the Baseline (-2 pts) x 2 = (-4 pts)

This option would require the hiring of three – four full-time staff personnel to operate the adolescent call center and develop resource materials (2 staff personnel to man the phones, 1-2 staff members to compile, develop, and maintain material resources). The average annual salary for a Foundation employee is about \$56,516 which amounts to about \$169,548 - \$226,064 in yearly costs (US Census Bureau, 2016). Quarterly maintenance of the call center's website and phone lines would fall under the Foundation's existing budget of \$5,400 annually. In total, this option ranges from \$174,948 - \$231,464.

### Effectiveness – Significant Positive Effect (+1 pts)

Overall, self-management interventions in adolescents with IBD have not been extensively evaluated. Two studies have shown self-management interventions to have some significant improvement in health-related quality of life but not across all measures and only for within-group comparisons (Plevinsky et al., 2016; Crohn's and Colitis Foundation 2019). In studies of adults, self-management interventions have shown significant ( $>0.2$ ) size effects, but it is unclear which components of the self-management interventions are causing the effects and how long effects last (Smith et al., 2002; Kennedy et al., 2004; Conley et al., 2016). In addition to these trials, the effectiveness of online or virtual interventions should also be considered. Two studies have examined the effectiveness of web-based self-management interventions, one in UC adults and another in ACDs (adolescents with chronic disease). Overall there is some significant evidence supporting this method, but it is not reliable.

### Feasibility – Equivalent to the Baseline (0 pts)

Feasibility is evaluated against the baseline according to the following questions. This alternative answered “yes” to three questions – equivalent to the baseline.

Is there existing infrastructure (i.e. staff, technical components, other resources) to help implement the option?

- **Yes**, the Foundation already has call center webpages and telephone lines in place.

Are Foundation employees likely to cooperate in administering the alternative?

- **No**, due to Covid-19, the Foundation is operating on a “maintain funds for mission critical programs” basis. Spending additional resources to open new programming would most likely not be approved by Foundation employees.

Is there a precedent that the Foundation can model the alternative after?

- **Yes**, the Foundation can model this alternative after its existing call center and the resources offered by the *Nothing Ventured Nothing Gained* program.

Does the alternative support the Foundation's overall mission statement and priorities?

- **Yes**, providing tools to help adolescents improve their management of IBD directly coincides with improving the overall quality of life of children with IBD without taking away resources from other patients.

### Children Reached – Fewer Children Reached in Numbers and Age (-2 pts)

#### *Uptake*

In 2018, the IBD Resource Center responded to approximately 12,000 inquiries. Using the logic and numbers established from the baseline, it is assumed about 600 children or caregivers of children will access the call center. It is also likely that the majority of

these children will fall within the targeted age demographic (14-18) since the average age of diagnosis for children with IBD is 15 years old (Crohn's and Colitis Foundation, 2014, 2019).

#### *Age Range*

This option would only target adolescents (ages 14-18) – reaching less age ranges than the baseline. Although it is unclear how many adolescents would have knowledge of this resource if provided, it is more likely that they would have access to this resource via a personal or school issued computer. Age maturity would also contribute to a child's ability to access this resource without their parents.

*\*Additional Note – Due to Covid-19, the Foundation's web access has increased five-fold, and the IBD Help Center is currently experiencing a surge in calls. It is likely more children and their caregivers would access the call center at this time.*

## ***Increase Practitioner Engagement through Continuing Medical Education Modules (CME's) and Training Programs***

### **Overall Score – (-2 pts)**

The Foundation's in-person and virtual preceptorship program seeks to improve physician training in the diagnosis, treatment, and management of IBD through in-person training and online accredited modules (CCFA, 2019). In terms of in-person programming, the Foundation offers an Advanced Practice Provider Preceptorship and Visiting IBD Fellow Program. These in-person programs seek to improve IBD care for all patients and increase the Foundation's role in IBD training across the country. In terms of online programming, the Foundation provides online modules covering four topics: Diagnosis and Medical Treatment, Long-term Disease Management & Surgery, Anemia, and Malnutrition (CCFA, 2019). The existing programming does not currently dedicate a section to mental health issues in children with IBD. The Foundation could develop a CME module and in-person training program for pediatric gastroenterologists and their support staff that specifically educates physicians on the increased rates of mental illness in children with IBD and recommended preventive care.

The Foundation could model this program after the American Diabetes Association's (ADA) efforts to close the gap between a growing need for mental health services for patients with diabetes and the number of mental health professionals trained in diabetes management. The program consists of an online CME module as well as an in-person seven-hour course. After completing the program, practitioners are then listed on the ADA's Mental Health Provider Directory, a directory listed on the ADA's website and available to patients and caregivers (American Diabetes Association, 2020). A program such as this not only increases practitioner knowledge of mental health issues in children with chronic conditions but provides patients, caregivers, and medical providers with a referral list of practitioners who can assist patients with mental health issues once they have been identified.

### **Cost – Greater than 2x the Cost of the Baseline (-2 pts) x 2 = (-4 pts)**

The costs of this alternative are relatively high. At least four staff personnel would need to be hired in order to develop the education module, go through the accreditation process, produce the necessary outreach materials to provide this resource to physicians, and oversee training events in person. Using the average annual salary of a Foundation employee, \$56,516, this option would total \$226,064 in personnel costs annually (US Census Bureau, 2016). In addition, website maintenance costs for this program would be included in the Foundation's existing budget (\$5400 annually). The

Foundation would also incur start-up costs to build out an additional webpage and add-ons to its current practitioner education pages. These additional costs are estimated at about \$875 (5 hours of work to build additional webpages and CME modules on existing platform). The Foundation could host training events at its local chapters or reach out to IBD Qorus hospitals (hospitals the Foundation has a working relationship with) for event space. In total, this option amounts to roughly \$232,339 annually. Costs are likely a little higher due to other potential resources and materials needed for training.

### **Effectiveness – Significant Positive Effect and Reliable ( +2 pts)**

The research surrounding this method is both statistically significant and reliable. Multiple studies point to the effectiveness of practitioner engagement as a preventive measure against mental illness in children with IBD (Engelmann et al., 2015; Farraye et al., 2017; Smith et al., 2002). CME's have also proven effective in improving clinical outcomes and the acquisition and retention of physician knowledge (Marinopoulos et al., 2007). This means that once practitioners receive this training, they are likely to implement it in practice.

### **Feasibility – Worse than the Baseline (-1 pts)**

Feasibility is evaluated against the baseline according to the following questions. This alternative answered “yes” to two questions – one question less than the baseline.

Is there existing infrastructure (i.e. staff, technical components, other resources) to help implement the option?

- **No**, while there are some existing components such as the Foundation's Preceptorship, Fellows, and CME programs, this is still a new initiative that would require the Foundation to produce a significant amount of infrastructure (staff, webpages, training modules, outreach, event schedule, event space, etc.).

Are Foundation employees likely to cooperate in administering the alternative?

- **No**, due to Covid-19, the Foundation is operating on a “maintain funds for mission critical programs” basis. Spending additional resources to open new programming would most likely not be approved by Foundation employees.

Is there a precedent that the Foundation can model the alternative after?

- **Yes**, the Foundation can model the program after the American Diabetes Association's existing physician training program for mental health issues.

Does the alternative support the Foundation's overall mission statement and priorities?

- **Yes**, providing practitioners with education to help adolescents with their mental health coincides with improving the overall quality of life of children with IBD.

## **Children Reached – More Children Reached in Age (+1 pts)**

### *Uptake*

In 2018, the Foundation reached over 40,000 medical professionals through its education programs. For the purpose of these calculations, it is assumed at least half of those medical practitioners serve children in some form. In 2018, physicians saw an average of 15.5 patients per day (Elflein, 2019). Multiplying that number by 261 working days a year amounts to 4,045.5 patients seen per year. For the assumed 20,000 pediatric medical practitioners the Foundation reaches, that amounts to 80,910,000 children seen. Using the statistic of 10 cases of IBD per 100,000 children, that amounts to roughly 8,100 children that will be reached.

### *Age Range*

This alternative would target children of all ages since enlightened practitioners would deliver care to children of all ages.



## Outcomes Matrix

A summary of the above analysis and resulting scores are provided below. Scores projected in the matrix are weighted.

Criteria	Weight	Baseline: Utilize Existing Online Resources and Support Groups	Provide Internet-Based Cognitive Behavioral Therapy	Create an Adjunct IBD Call Center for Adolescents	Increase Practitioner Engagement through Continuing Medical Education Modules and Training Programs
Cost	2	0	-2	-4	-4
		\$5,400	\$7,005	\$174,948 - \$231,464	\$232,339
Effectiveness	1	0	2	1	2
Feasibility	1	0	1	0	-1
Children Reached	1	0	-1	-2	1
	Total Score	0	0	-5	-2
	Rank	1 - tied	1 - tied	4	3



## Recommendation

### *Utilize Existing Online Resources and Support Groups and Provide ICBT*

From this analysis, it is recommended that the Foundation keep its existing online resources and support groups while also implementing new ICBT sessions. Although the Foundation's existing resources have not yet been evaluated, the current pandemic does not allow the Foundation to consider some of the more expensive alternatives proposed at the moment. However, the Foundation's existing resources have been reaching a substantial amount of children, and the recent shift to social distancing and online access has caused demand for the Foundation's online resources to increase. In fact, participation in the Foundation's "townhalls" and social media programs (Facebook Live, etc.) have increased by 1,200 percent since the Covid-19 outbreak.

This recent increase in online-demand makes a strong case for why the Foundation should also implement ICBT sessions as soon as possible. Due to Covid-19, many children with IBD who currently make use of a psychologist or therapist for IBD related emotional wellbeing may not be able to reach their providers. Since many children with IBD are immunocompromised, it is likely they and their families are taking stricter self-isolation measures, which could lead to increased anxiety and depressive symptoms. The Foundation's offering of this free online resource could help mitigate the problem.

Although implementing ICBT does come with a start-up cost, it would only add roughly \$1,605 to what the Foundation is spending on its existing online support resources. In addition, ICBT makes up for its cost in effectiveness. As reported in this analysis, ICBT has a significant effect on the mental wellbeing of children with IBD, and with an online-demand surge, the Foundation has a unique opportunity to positively impact thousands of children and their families. If the Foundation can manage enough emergency funding to keep its existing resources running, it should look seriously toward ICBT as the next most effective and necessary programming for its users.



## Implementation

### *Next Steps*

The Foundation's Development Manager should reach out to its volunteer list of registered physicians with the proposal for ICBT sessions. If possible, given the Foundation's recent use of Facebook Live to offer webinars and other workshops during the Covid-19 outbreak, the Foundation could even put together some live ICBT sessions for those struggling during this time. Since the Foundation is committed to acting quickly on this issue and providing resources to IBD patients during the Covid-19 outbreak, there should be limited administrative red tape during implementation.

In addition, the Foundation should do its best to develop the new online platform to engage parents and children in the most user-friendly way possible. The Foundation should develop a survey requesting feedback from parents and children to assess the new online platform and make appropriate changes as designated. Since there is a significant amount of stigma surrounding mental illness, the idea of CBT may seem frightening or unappealing to certain stakeholders. The Foundation could place content on the ICBT platform describing the risk of mental illness in children with IBD, explaining its causes, and offering CBT as a natural and effective solution for anyone, regardless of an official mental diagnosis or previous visits to a psychologist or therapist. The Foundation could also provide testimonials from patients who have used these resources. Through these measures, the Foundation can offer this new resource without intimidating children and their families.

Lastly, the Foundation should make sure that this new program, as well as its existing programs and resources, are extensively evaluated. The Foundation should collect data on its existing online support groups, its online material resources, and any new ICBT sessions that are implemented. This data should include online user's perspectives of what they found useful from each resource/support group session and what they would like to see improved. It should also include how often users accessed these different resources and over what time period. Lastly, this evaluation should take course over the next year with the hope that all resources will be reevaluated at the end of this time period. Based on this reevaluation and whether current world circumstances change, the Foundation can decide whether to continue with these alternatives and potentially revisit other alternatives discussed in this report.

## *Challenges*

While CBT is promising, it is not perfect. CBT has only been extensively studied in children 8 years and older. This means that those under 8 years old will be left out of this option unless a caregiver participates in ICBT sessions. In addition, younger children will face more challenges accessing and utilizing ICBT sessions than more mature users. It is also unclear how many children in the 8-18 age range will ultimately access this resource. Certain patients may have limited knowledge of these resources, and it is unlikely that younger children themselves will individually enroll in support groups. Since most children must rely on their caregivers or physicians to provide these resources (i.e. owning a personal computer or laptop and gaining awareness of the Foundation's existence), they are one step removed from having immediate access to this resource. Therefore, this option depends heavily on caregiver and practitioner knowledge of the Foundation and its resources.

## *Solutions to Challenges*

In order to better increase the chance that children will have access to these online resources, the Foundation should send out a notice to its caregiver email list that provides targeted information on the risk of mental illness in children with IBD, tips for starting a conversation around emotional wellbeing with children, and links to existing resources and any new ICBT resources. Since younger children are less likely to be on the internet or know how to access the Foundation's website, this outreach to caregivers can help younger children better interact with the Foundation's programming.

Alongside caregivers, it is also important to consider the other adults who will have the most impact on children with IBD. There are many studies that point to the effectiveness of practitioner engagement as a preventive measure to avoid mental illness in children with IBD (Engelmann et al., 2015; Farraye et al., 2017; Smith et al., 2002). Since practitioners are ultimately the ones on the front lines of patient care, it is important to figure out how to bridge the gap between the resources the Foundation provides and physician knowledge of these resources. The Foundation should consider tailoring its physician outreach materials to include the importance of preventive mental health care for IBD patients and information on the Foundation's existing resources and any new ICBT resources. Patients put their trust in their physicians, and they are most likely to take up the Foundation's resources if recommended by practitioners. By increasing practitioner outreach and awareness, the Foundation improves its ability to reach both patients and physicians. If both of these relationships are improved, the mental health care needs of children with IBD will more increasingly be met.

## Appendices

### Appendix A: Case Study for Family-Based Interventions - *Nothing Ventured Nothing Gained Program*

#### Overview

In Australia, a non-profit which focuses on improving mental health outcomes partnered with several other organizations to improve the mental health outcomes of children with T1D. The project was called “Nothing Ventured Nothing Gained” (NVNG) and involved adolescents aged 13 to 18 years old with T1D. Patients were randomly selected through two pediatric diabetes clinics at the Royal Children’s Hospital and Monash Medical Centre in Melbourne, Australia. The goals of the program were to reach T1D adolescents who traditionally lack easy access to health services due to social or geographical isolation and manage the psychological impact of T1D. This was done through a web-based intervention that included an adolescent mental health prevention program and an adolescent parenting program. Both the parent and adolescent programs included self-directed module sessions (6 for parents, 5 for adolescents) to be completed over six weeks. The module sessions provided a mixture of educational material about mental health in T1D patients and their families, learning activities, audio modelling, and quizzes with feedback. Both parents and children were encouraged to self-reflect on the outcomes of their modules and practice what they had learned from the modules with their families between sessions. The aim of the parenting modules was to empower parents to support the resilience and wellbeing of their children and strengthen overall family relationships. The aim of the adolescent modules was to use CBT approaches to manage normal adolescent stressors along with disease demands.

#### Parent Module Topics

1. Raising a teenager with diabetes
2. Strengthening your relationship with your teenager
3. Influencing your teen in positive ways
4. Communication and problem solving
5. Boundaries
6. Looking after yourself

#### Adolescent Module Topics

1. Being a teen and living with diabetes
2. Thoughts, feelings, and behavior
3. Getting along with friends and family
4. Building strong relationships
5. Staying healthy – the balancing act

## **Results<sup>2</sup>**

In terms of access, 45 percent of adolescents and 57 percent of parents selected to participate went on to access the program. However, the number who completed the full program was significantly lower, with 21 percent of adolescents and 42 percent of parents completing the full program. In terms of satisfaction, 72 percent of adolescents and 68 percent of parents said they would recommend the program to other patients and families in their situation. In terms of general health perception, family activities, and bodily pain, those who completed the program showed improvements across all categories compared to those who did not complete the program. Adolescents in the completer group also had better outcomes on an “Adolescent Resilience Scale” compared to non-completers. Overall, the NVNG program showed promising results as an intervention for mental health outcomes in children with T1D.

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<sup>2</sup> This case adapted from the NVNG Evaluative Report [https://www.beyondblue.org.au/docs/default-source/research-project-files/bw0281.pdf?sfvrsn=6f886cea\\_2](https://www.beyondblue.org.au/docs/default-source/research-project-files/bw0281.pdf?sfvrsn=6f886cea_2)

## Appendix B: Description of Effectiveness Measures

The effectiveness of proposed alternatives was primarily measured by reading through existing clinical studies that have evaluated these methods. The majority of clinical studies used common wellbeing measures such as HRQoL, CDI, and SCAS to distinguish whether an intervention improved overall mental health. These measurements are defined below. The following terms are primarily adapted from the CDC and SCAS websites.

**Health-Related Quality of Life (HRQoL):** “Health-related quality of life (HRQOL) is an individual’s or a group’s perceived physical and mental health over time.” HRQoL is measured by asking individuals about their “wellbeing” or “what people think and feel about their lives, such as the quality of their relationships, their positive emotions and resilience, the realization of their potential, or their overall satisfaction with life.”<sup>3</sup> The CDC uses a set of questions called the “Healthy Days Measures.”<sup>4</sup> These questions include the following:

- “Would you say that in general your health is excellent, very good, good, fair or poor?”
- Now thinking about your physical health, which includes physical illness and injury, how many days during the past 30 days was your physical health not good?
- Now thinking about your mental health, which includes stress, depression, and problems with emotions, how many days during the past 30 days was your mental health not good?
- During the past 30 days, approximately how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?”<sup>5</sup>

**Spence Children’s Anxiety Scale (SCAS)** – “The SCAS is intended as an indicator of the number and severity of anxiety symptoms. It may also be used for identification of children who have elevated symptoms of anxiety and for whom further assessment is recommended to determine whether there is a need for intervention. Similarly, it provides an indicator of response to treatment. SCAS is measured by using t-Scores which enable the comparison of a young person’s scores against norms from an equivalent age and gender group. A T-score of 10 above the mean of 50 represents a

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<sup>3</sup> Adapted from the CDC’s website. Access more information at <https://www.cdc.gov/hrqol/wellbeing.htm>

<sup>4</sup> Adapted from the CDC’s website. Access more information at <https://www.cdc.gov/hrqol/methods.htm>

<sup>5</sup> Adapted from the CDC’s website. Access more information at <https://www.cdc.gov/hrqol/methods.htm>

value of approximately 1 standard deviation above the mean and is indicative of elevated anxiety.”<sup>6</sup>

**Children’s Depression Inventory (CDI)** – “The CDI is a self-report assessment for children. The CDI has two forms: The original 27-item version, and the 10-item short-form version, which takes between 5 and 15 minutes for the child to complete. The CDI is designed to detect symptoms of depression and to distinguish between depression and other psychiatric disorders. It can also be used as an instrument to monitor changes in depression symptoms over time. Each item in the CDI has three statements, of which a child is asked to select the one answer that best describes their feelings over the past two weeks.

There are five subscales within the assessment that measure different components of depression:

- Anhedonia (inability or decreased ability to experience joy)
- Negative self-esteem (the belief that you are not good at anything)
- Ineffectiveness (lack of motivation or inability to complete tasks)
- Interpersonal problems (difficulty making and keeping close relationships)
- Negative mood (irritability or anger)

The CDI is popular in part because it is easy to administer and score. A child with age-appropriate reading abilities can complete the scale relatively quickly.”<sup>7</sup>

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<sup>6</sup> Adapted from the Spence Children’s Anxiety Scale website found at [https://www.scaswebsite.com/index.php?p=1\\_9](https://www.scaswebsite.com/index.php?p=1_9)

<sup>7</sup> Adapted from VeryWell Mind. For more information see <https://www.verywellmind.com/the-childrens-depression-inventory-cdi-1066780>



## Appendix C: Overview of the Foundation's Existing Online Mental Health Webpages

Coronavirus and IBD: Information and Event Updates

CLICK HERE

ABOUT US

LOCAL RESOURCES

NEWS & EVENTS

OUR IMPACT

SIGN IN

CROHN'S & COLITIS

FOUNDATION

PATIENTS & CAREGIVERS

RESEARCH

PROFESSIONALS

GET INVOLVED

GIVE NOW

→

Q

### Mental and Emotional Well-being

Living with a chronic, and often painful, illness can take a toll on your mental health and emotional well-being. **You are not alone.** We understand how challenging and frustrating it can be to manage not only the physical symptoms of Crohn's disease or ulcerative colitis, but also the stress, worry, depression, and anxiety that you may feel along the way.

In addition to depression and anxiety, emotional responses to living with a chronic illness can include denial of your disease, the need for dependence or dependent behaviors, feeling overwhelmed, and having a poor self-image. Inflammatory bowel disease (IBD) can also emotionally affect your family and friends.

**If you have thoughts of self-harm or suicide, please do not hesitate to reach out for help by calling 911, going to the closest emergency room, or calling the suicide hotline at 1-800-SUICIDE.**

Depression and Anxiety

Navigating Daily Life with IBD

Coping Strategies to Improve Mental Health

Talking to Your Healthcare Team

Resources and References

#### Sign up for our e-Newsletter

Let's keep in touch! Enter your email and zip code to get updates from your local chapter, read the latest on our IBDVisible blog, and hear what's new at the Foundation.

E-MAIL ADDRESS

ZIP CODE

SUBMIT

→

8

<sup>8</sup> Retrieved from <https://www.crohnscolitisfoundation.org/mental-health>

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# Stress Reduction Techniques

Stress and anxiety do not cause Crohn's disease or ulcerative colitis, but they can negatively impact your physical health and cause further gastric distress. These mindfulness techniques can help you learn to relax.

## Diaphragmatic Breathing

The ability to relax and clear your mind is a helpful coping skill for managing stress. Living with a chronic illness can make it difficult to know how to relax or even where to begin.

Diaphragmatic breathing, which is also known as deep breathing or belly breathing, offers many physical and emotional benefits, making it a great place to start.

- Lowers heart rate and blood pressure
- Decreases muscle tension
- Oxygenates your blood
- Brings warmth to your hands and feet
- Increases energy and motivation
- Improves concentration
- Strengthens the immune system
- Reduces stress hormones

The activation of the diaphragm through diaphragmatic breathing also allows for a gentle massage of the internal organs, including the intestines and stomach, which can help with abdominal pain, urgency, bloating, and constipation.

### How to Diaphragmatic Breathe

Diaphragmatic breathing is a skill that requires practice. It will become easier over time. When you are first learning to diaphragmatic breathe, you may feel some uneasiness or lightheadedness, which is perfectly normal. Allow yourself time to acclimate after your session and take care not to stand up too quickly.

1. Sit or lie in a comfortable place. Close your eyes.
2. Place one hand on your chest and one hand on your abdomen. Your bottom hand should do the moving. Top hand should remain still or only move as the bottom hand moves.
3. Inhale through your nose for about 4 seconds and feel your abdomen expand. You may feel slight tension during these initial inhalations.
4. Hold your breath for 2 seconds.
5. Exhale through your mouth very slowly for about 6 seconds. Your mouth should be relaxed with a steady, slow exhalation.
6. Repeat for 5 to 15 minutes.

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<sup>9</sup> Retrieved from <https://www.crohnscolitisfoundation.org/mental-health/coping-strategies-for-better-mental-health>

Mental Health

## Navigating Daily Life with IBD

## Coping Strategies to Improve Mental Health

## Talking to Your Healthcare Team

## Resources and References

The Crohn's & Colitis Foundation offers the information and links below for educational purposes only. This information should not replace discussions with your doctor and healthcare team to understand your specific patient needs as it relates to your mental health.

You can ask your healthcare team to recommend a mental health professional, or you can look online using these resources.

A global directory of mental health providers experienced in psychology and gastroenterology.

- **The impact of anxiety and depression on patients with inflammatory bowel diseases**
- **Psychological considerations and interventions in inflammatory bowel disease patient care**
- **Getting Personal: A review of sexual functioning, body image, and their impact on quality of life in IBD patients**
- **Similar risk of depression and anxiety following surgery or hospitalization for Crohn's disease and ulcerative colitis**

## Fact sheet

Emotional  
Factors  
(.pdf)...

Fact sheet  
on  
emotional  
factors

PDF

## Infographic

**Mental Health and IBD Infographic.**

Mental health and IBD infographic

PDF

## Appendix D: Overview of the Foundation's Existing Online Support Group Sessions for Patients and Caregivers

### Online Patient and Caregiver Support Group Monthly Programming:<sup>11</sup>

#### Week 1: IBD 101

Thu, April 9, 2020 8:00-9:30 PM EST, 5:00-6:30 PM PST

##### DESCRIPTION:

This session will help you learn more about the basics of living with Crohn's disease and ulcerative colitis. In addition to sharing experiences of being diagnosed and dealing with IBD, these discussions can help you generate questions for your health care team and form a plan of action for your own disease management.

#### Week 2: Medical Management

Thu, April 16, 2020 8:00-9:30 PM EST, 5:00-6:30 PM PST

##### DESCRIPTION:

Discussions in this session will help inform you about different treatment options. You will learn more about the main medication categories, surgical options, alternative medicines and more. As always, personal experiences are a valuable part of the overall conversation, so be sure to share them with one another.

#### Week 3: Diet and Nutrition

Thu, April 23, 2020 8:00-9:30 PM EST, 5:00-6:30 PM PST

##### DESCRIPTION:

Learn about how changes in diet can affect IBD. This session will help clarify the difference between diet and nutrition, and give you a chance to share tips for how to adjust eating habits during flare-ups. After this session, you'll be ready to take on the challenges that may come with eating and IBD.

#### Week 4: Living with IBD

Thu, April 30, 2020 8:00-9:30 PM EST, 5:00-6:30 PM PST

##### DESCRIPTION:

For the final session of this online support group series, we'll discuss how to live well with IBD. Find out about important support resources, how to create a support system, and other coping techniques. Share advice and learn from one another when it comes to maintaining the best possible quality of life.

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<sup>11</sup> Adapted from <https://www.crohnscolitiscommunity.org/chatseriesdetail?ChatSeriesID=228>

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