



Losing Childhood to America's OCD Care Crisis

The State of Pediatric OCD Care
in the United States

October 2026



About the International OCD Foundation (IOCDF)

The International OCD Foundation is the leading authority on obsessive compulsive disorder (OCD) and related disorders. As a 501(c)3 nonprofit organization, the IOCDF supports a global community of people with lived experience, families, mental health professionals, and researchers. The IOCDF is committed to expanding access to effective treatment, advancing research, and ensuring that no one affected by OCD and related disorders suffers alone. Visit iocdf.org.

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This project was developed in collaboration with



Our sincere thanks to the anonymous family whose generosity funded this publication.

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Executive Summary

Approximately 2 million children and adolescents in the United States are estimated to have obsessive compulsive disorder (OCD),^{1,2,3} a mental health disorder that causes significant impairment to a child's day-to-day functioning, including relationships, school, health, and cognition.⁴

In this pediatric-focused followup to the International OCD Foundation's groundbreaking report, [America's OCD Care Crisis: National Findings on the Failure of Effective OCD Treatment to Reach Patients](#),⁵ the IOCDF, in collaboration with the Guardian Research Network (GRN) and Resonance, analyzed data from 2.3 million patients who were ages 0-18 during the ten-year study period (2015–2025). The analysis examined the estimated percentage of children and adolescents in the U.S. who are diagnosed with OCD, their demographics, and how many receive recommended, evidence-based treatments.

We uncovered a concerning reality for kids and teens suffering with OCD in the U.S.:

- Just **0.74%** of all the children and adolescents in the database were diagnosed or detected by clinicians to have OCD, **well below the expected population prevalence of up to 3%**.
- Only **4%** of children diagnosed or identified with OCD had documented evidence of receiving **Exposure and Response Prevention (ERP)**, the specific type of cognitive behavioral therapy (CBT) that is the gold-standard treatment for OCD.
- More than **64%** of those diagnosed or identified with OCD were **never referred for ERP or any type of CBT**, despite most receiving a documented mental health assessment.

These systemic challenges are serious, but they have solutions. Through targeted action we can improve these unacceptable outcomes for children and adolescents with OCD and connect more with the effective, evidence-based treatment that can help them thrive.

The IOCDF offers the following recommendations:

1. Routinely screen all children for OCD in all pediatric and mental health settings.
2. Train all mental health clinicians in how to assess, diagnose, and treat pediatric OCD.
3. Enforce adherence to established clinical practice guidelines for pediatric OCD.
4. Increase affordable access to effective care.
5. Provide families with the resources and education they need to actively support themselves and the individual with OCD.
6. Raise accurate public awareness about what OCD really is.
7. Equip educators and school professionals to recognize OCD and connect students with support.

The scale of the problem revealed by this study makes clear that progress depends on collective action across the field. Clinicians, health systems, educators, researchers, policymakers, advocates, families, caregivers, payors, and people with lived experience all have a role to play. Together, these efforts can help ensure that children and adolescents with OCD reach effective treatment sooner, reducing years of unnecessary confusion and distress.

Background

“It is my hope that every child who is suffering from OCD can find access to the correct treatment. That they can learn to apply the tools to fight OCD and reclaim their childhoods, and in turn their lives. To live the life they want on their own terms and not on the terms of their OCD.”

– Kjersti Helberg with her son, Jaden



Obsessive Compulsive Disorder in Children and Adolescents

What is OCD?

Obsessive Compulsive Disorder (OCD) is an often misunderstood, serious mental health condition that affects nearly 240 million people worldwide. With a prevalence rate of up to 3%, children and adolescents are just as likely as adults to experience OCD.^{1,2,3}

People with OCD experience intrusive and unwanted thoughts (obsessions) and perform repetitive behaviors (compulsions), including avoidance, to minimize or prevent the distress caused by obsessions. OCD symptoms sometimes take up several hours a day and can significantly decrease a person's quality of life.⁶

90% of children and adolescents with OCD report impairment in at least one aspect of their lives, such as relationships, health, and cognition — and most especially in school.^{4,6,7} Youth with OCD are significantly less likely to pass courses, complete high school, or begin postsecondary education compared to those without the disorder.⁸ Most concerning, in a sample study of children with OCD, 13% reported having strong suicidal ideation.⁹

Despite its prevalence and major impacts on a person's quality of life, ability to function, family, and even mortality, OCD goes untreated for an average of seven years in adults^{10,11,12} and over two years in children^{13,14} in those who actually receive an accurate diagnosis. Previous research indicates that only a tiny fraction of children and adolescents with OCD receive an accurate diagnosis and effective therapy.^{2,15,16,17} The duration of untreated OCD in children and adolescents is one of the strongest predictors of long-term persistence of OCD.^{18,19} Left untreated, OCD tends to follow a chronic course, leading to substantial functional impairment and increased susceptibility to other mental disorders in adulthood.^{18,19}

How OCD Might Look in Kids and Teens

Symptoms of OCD in children and adolescents are wide ranging but may look like:

- Checking things repeatedly (such as their backpack, lunch bags, or locks)
- Redoing homework over and over until it feels perfect or “just right”
- Asking a lot of questions to understand what “right” looks like
- Repeatedly and excessively asking for reassurance
- Not touching things others have touched, or needing to clean them off first
- Counting or repeating numbers over and over in their head
- Confessing or apologizing repetitively and excessively
- Refusing food due to fears of contamination
- Persistent fears of terrible things happening to themselves or loved ones
- Doing things exactly the same way each time — such as walking through doors or touching things

Caregivers and professionals working with kids may also notice:

- A youth becoming upset, frustrated, and/or angry if they are prevented or unable to do things the way they feel they need to
- School avoidance, or being late due to performing extensive rituals

OCD's Impact on Families

OCD in children and adolescents impacts the whole family, often causing significant emotional distress and impairment in family functioning.^{23,24,25} Nearly half of mothers and one third of fathers of youth with OCD reported daily occupational impairment as a result of having to manage their child's OCD symptoms.²⁶

Parents, family members, and caregivers of youth with OCD frequently do not understand the condition well. A common belief among family members is that OCD symptoms originate from personality characteristics instead of stemming from a true mental health disorder.²⁷ Even when family members sense that something is truly wrong, they often do not know how to identify the symptoms or how to help. Many unintentionally reinforce the youth's OCD via accommodation behaviors — actions taken by loved ones that allow the youth to avoid triggers of obsessions and anxiety.²⁸ Accommodations may include providing reassurance, performing a compulsion to ease their child's distress, altering daily routines, and avoiding triggering their child's obsessions.²⁹ These behaviors unintentionally feed into and perpetuate the child's OCD cycle and can interfere with treatment.

BY THE NUMBERS

- **3%:** The prevalence rate of OCD, for adults as well as children and adolescents.^{1,2,3,20,21,22}
- **64%:** The percentage of OCD cases that begin by age 25, 50% by age 19, and 25% by age 14.²⁰
- **90%:** The percentage of children and adolescents with OCD who report impairment in at least one aspect of their lives (such as relationships, cognition, or school).⁴

How OCD is Treated in Youth

For youth with OCD, appropriate treatment* can improve quality of life and allow them to thrive. The first-line treatments for children and adolescents with OCD are exposure and response prevention (ERP) — a specific type of cognitive-behavioral therapy (CBT)^{30,31,32,33} — and serotonin reuptake inhibitor (SRI) medication when needed.^{17,34,35}

These treatments are highly effective, with substantial rates of response and remission for CBT alone, SRI medication alone, and highest for combined treatment with CBT and medication.^{36,37,38}

Medication is often needed when the child has moderate-to-severe symptoms, is unable to engage or participate in ERP, and when ERP is unavailable, refused, or has had little impact on the child's symptoms. Medications are also often needed to treat comorbid conditions that can be severe or get in the way of the child's success with ERP, such as major depressive disorder.^{31,32,33} Medications can be used alone, but have greater effect when combined with ERP.^{36,37,38}

EXPOSURE AND RESPONSE PREVENTION (ERP) FOR YOUTH

ERP is designed to help people reduce symptoms and improve daily functioning through a process that involves gradually and systematically approaching obsessional triggers while refraining from compulsions and avoidance. In doing so, the child learns that feared outcomes are unlikely to happen and that they can cope with distress.

A licensed clinician guides youth through this process, and kids learn that they can allow obsessions and the feelings they cause to come and go without having to give in to the urge to do their compulsions.

ERP for youth requires clinicians to be competent in designing developmentally appropriate exposures and in using therapeutic tools based on the child's age and developmental stage. For example, a common technique is having the child externalize their OCD as a separate entity (such as a villain from a popular movie, a monster, etc.), giving it a name, and calling back to that named entity as a concrete force to push back against throughout the course of treatment.

Families are engaged as key therapeutic allies ("co-therapists," coaches, etc.) in helping kids work through their treatment plan between sessions, reinforce new skills, and encourage the child to keep overcoming their OCD. Family involvement is also critical to help recognize and reduce family accommodation behaviors.³⁹

*Please visit iocdf.org/about-ocd/ocd-treatment-guide to view IOCDF's treatment guidelines, including medication dosages that are recommended for pediatric OCD treatment.

Methodology / About this Paper

In December 2025, the International OCD Foundation released [America's OCD Care Crisis: National Findings on the Failure of Effective OCD Treatment to Reach Patients](#),⁵ reporting the results of an analysis of the largest sample of patients with OCD ever studied.

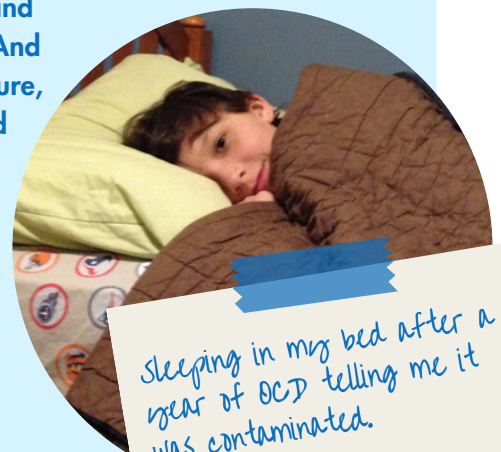
This white paper — [Losing Childhood to America's OCD Care Crisis](#) — takes a deeper look at the children and adolescents within that dataset to understand the current landscape of diagnosis and treatment for youth with OCD in the United States.

It all started with a library book...Honestly, I don't remember it too well. I just remember picking up that library book and having this tingling feeling on the tips of my finger while some voice in my head told me that something was wrong, that my hands were dirty. The voice told me to wash my hands so I did. And the next time I went to pick up that library book, that same voice told me it was dirty and that I ought to avoid it. So, I did.

Soon more things began to feel dirty. Within a few weeks I was avoiding anything I had touched after touching that book. A few weeks later and I was avoiding things I had touched after touching things outside. Quickly, my world became divided into "clean things" and "dirty things" and I could only touch those "clean things" when I was "clean." But I so rarely was "clean" because, to be clean, I had to follow some elaborate set of rules about how many times I needed to wash my hands and what I could wear and how long I had to shower. And no matter how hard I tried to follow these rules, something always made me feel "dirty" and I had to start the process again. And again. And again.

By my 14th birthday, I was hardly able to leave my house, talk to my friends, or do much of anything that had previously brought me some comfort. I spent most days sitting on the floor, waiting for time to pass. Soon thereafter, I was diagnosed with OCD and began exposure and response prevention therapy. Well, began might be a stretch. Because despite how miserable I was trying to keep track of all these rules, I was more scared to break them. In fact, I didn't think I could. No matter how many times my parents and therapists told me I could get better, I didn't believe them. I lied to my parents and therapists about getting better for about six months, but they never gave up on me. Gradually, I began to break some of OCD's rules. I broke the smallest rules first and cried and yelled and panicked while doing so, but I did it. And then did it again. And again. And again. Slowly but surely, I began to make some progress. Sure, I slipped up from time to time, but I was soon taking more steps forward than I was back. Importantly too, the more rules I broke, the more it became clear to me that I was stronger than my OCD. I could beat it, and so I did. By my 15th birthday, OCD no longer determined my schedule — I did. I don't think I could have gotten to that point had it not been for others — clinicians, parents, close friends — believing in me when I couldn't believe in myself.

— Kyle King



Sleeping in my bed after a year of OCD telling me it was contaminated.

Study Design and Data

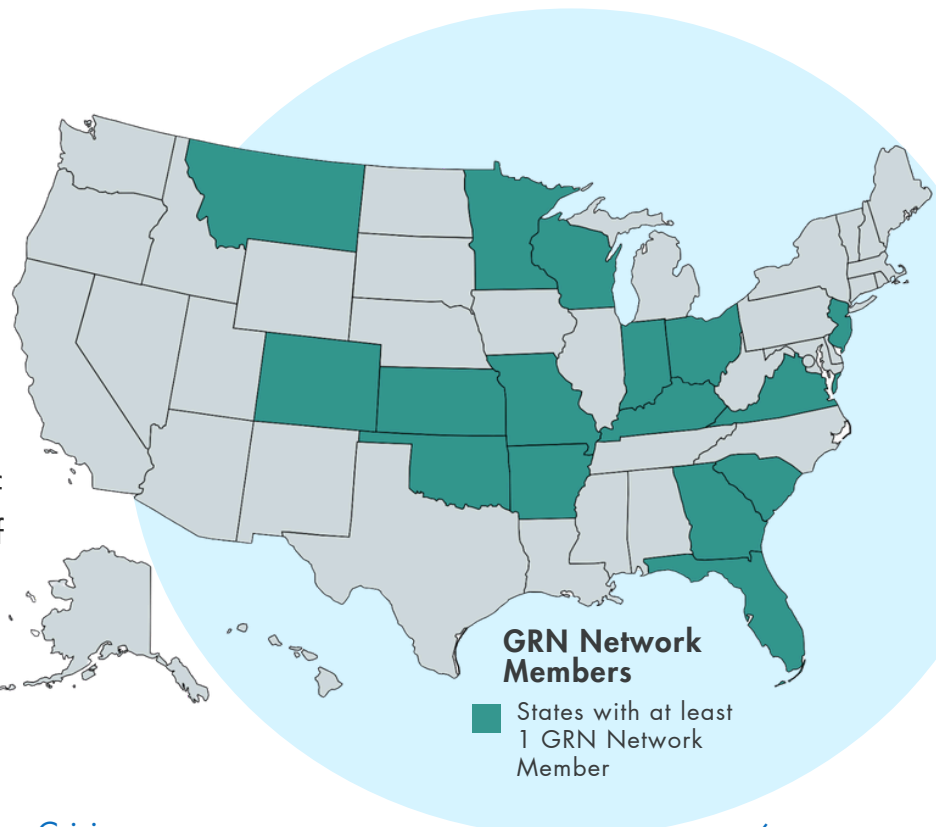
In 2025, the IOCDF performed a retrospective, population-based cohort study designed to estimate the prevalence of OCD, characterize the affected population, and analyze diagnostic and treatment trends over a 10-year period, from January 1, 2015, to January 1, 2025.

The study utilized de-identified Electronic Health Record (EHR) data from the Guardian Research Network (GRN)⁴⁰, a consortium of 14 integrated health delivery networks (IDNs) across 16 states within the U.S. Thirteen of the 14 health systems are community-based IDNs, while the remaining health system is an academic medical center. The GRN database contains longitudinal EHR data for approximately 18 million adult and pediatric patients, residing in all 50 states, including rural, urban, and suburban areas. It contains longitudinal and complete patient records, spanning across inpatient and outpatient encounters, encounters with specialists and primary care providers, as well as urgent care and emergency department visits. The GRN database reflects a diverse population in terms of age, gender, geography, insurance coverage, and racial / ethnic distribution. Patients in the GRN may be insured by private insurance, Medicaid, Medicare, Tricare, or may be uninsured.

The overall database aligns very closely with U.S. census data in terms of gender, urban vs. rural distribution, percentage who are Black, Native American, or Pacific Islander. However, it under-represents Hispanics, Asians, multiracial persons, and children, but over-represents Whites and people over 65.

The database is linked to the Area Deprivation Index (ADI),⁴¹ which allows for grouping of data by socioeconomic status.

The dataset used for *America's OCD Care Crisis*⁵ and this current report comprises 10 years of EHR data from 10.4 million unique individuals in the GRN database who had encounters in healthcare settings between January 1, 2015 and January 1, 2025. This report specifically analyzes the 2.3 million patients in the GRN database who were aged 0-18 during the ten year period of the study, with the objective of determining the estimated percentage of people aged 18 or under in the U.S. who have been diagnosed with OCD, their demographics, and how many of them have received the recommended, evidence-based treatments for OCD.



The Analysis

To help ensure as many cases of OCD were found in the EHR records, a dual-method algorithm was used. OCD diagnoses were identified either by the presence of at least one International Classification of Diseases, Tenth Revision (ICD-10) code for OCD, or through a natural language processing (NLP) analysis of clinical progress notes. A proprietary large language model (LLM) was used to detect key terms and clinical narratives consistent with an OCD diagnosis (e.g., intrusive thoughts, compulsions, ERP). LLM analysis of EHR notes was also used to identify referral, recommendation, and receipt of CBT, ERP, and other treatments.

My older brother was diagnosed with OCD when I was five years old. So, for as long as I can remember, OCD has been an unwelcome member of our family. First, he asked questions repeatedly, asking for various reassurances, but we had no idea that it was a sign of OCD. This went on for months. Then, he began running to the kitchen faucet and “wetting” his hands with the drops of water left at the edge of the faucet. That’s when my mom realized that his unusual behaviors might be related to OCD. He immediately began therapy, and his symptoms began to improve. However, throughout middle school and high school, they came back with a vengeance. It was difficult for him to maintain friendships, complete his homework, and function like a normal teenager. I watched my parents struggle as my brother cycled through different therapists and treatments. Thankfully, my brother eventually received the support he needed and is now doing much better.

– Ella Kim



Findings: Unacceptable diagnosis and treatment gaps exist for children and adolescents suffering from OCD.

Pediatric OCD is severely under-diagnosed in clinical settings.

Pediatric OCD appears to be substantially under-identified and under-diagnosed in clinical settings. Of the 2.3 million unique individuals in the GRN database who were aged 0-18 at some point during the 10-year study period, only 12,681 (0.55%) received a formal diagnosis of OCD. A natural language processing analysis of clinical notes identified an additional 4,265 children and adolescents whose records indicated they definitely or very likely had OCD, despite not having received a formal diagnosis. Together, these groups represented 16,946 children and adolescents, or 0.74% of all children and adolescents in the database.

This represents a small fraction of the up to 2-3% pediatric OCD prevalence expected based on population estimates. While this study was not designed to determine whether individual children or adolescents may have been later diagnosed or to measure the number of cases missed over time, the **substantial gap between expected prevalence and clinical identification suggests that many may go misdiagnosed or unrecognized in clinical care.** When OCD is not recognized, kids, teens, and families may face delays in accessing appropriate, evidence-based treatment.

Our findings replicate and extend those of prior studies that found that only a tiny fraction of children and adolescents with OCD ever receive an accurate diagnosis and effective therapy.^{2,15,16,17,42} Previous research has found that OCD is often misdiagnosed by clinicians.⁴² In studies that presented case vignettes of individuals with OCD to clinicians, 35-40% of OCD case vignettes were misidentified by clinical psychologists^{43,44} while over 50% were not correctly identified by primary care physicians.⁴⁵

OCD may go undiagnosed or undetected in children and adolescents if they hide their symptoms or are not asked direct questions to screen for OCD symptoms. A large prior study found that children with OCD often hide their OCD symptoms, so parental reports done without interviewing the child markedly underestimate the true prevalence.⁴⁶ Many children may be embarrassed about their symptoms or unaware that what they are experiencing isn't typical, which can make them hesitant to speak up about them. When interviewed, adolescents with OCD report that their OCD behaviors are misunderstood by themselves and others, leading to delays in finding help.⁴⁷ They report a sense of shame that led them to keep their OCD secret due to feeling "crazy."⁴⁸ Moreover, 10-38% of youths with OCD exhibit poor insight into their OCD symptoms.^{48,49}

OCD symptoms can overlap and coexist with other mental health disorders, making it harder to receive an accurate diagnosis or appropriate care. Youth with OCD have significantly higher rates of co-occurring anxiety disorders, major depressive disorder, eating disorders, and post-traumatic stress disorder⁵⁰ than children in the general population.^{17,51,52} They are also more likely to have other neurodevelopmental disorders, such as ADHD, autism spectrum disorders, and Tourette syndrome and other tic disorders than children without OCD.^{52,53} Clinicians sometimes focus on the co-occurring disorders and miss the OCD.

The vast majority of children and adolescents with OCD do not receive the recommended therapy for OCD.

Even when OCD is diagnosed or identified, most kids and teens do not have documented evidence of receiving the most effective treatment. Remarkably, only 4% of children and adolescents with OCD in this study had documented evidence of receiving exposure and response prevention (ERP), the specific form of cognitive behavioral therapy (CBT) that is the first-line, most effective treatment for OCD.⁵⁴ Only 25% had documented evidence of receiving any form of CBT, which may or may not have included ERP. More than 64% had no documented referral for ERP or any form of CBT, despite 62% having a documented mental health assessment.

This suggests that **most mental health clinicians are not following the well established practice guidelines for pediatric OCD**^{30,31,32,33} and are failing to either provide or refer children and adolescents with OCD for the most effective therapy for their condition. The longer OCD goes untreated, the greater its severity and functional impairment become^{10,12,55} and the greater the likelihood it will persist,¹⁹ making early recognition and treatment critically important.⁵⁶

Practice guidelines strongly recommend CBT with ERP as the first-line treatment for children and adolescents with OCD,^{30,31,32,33} yet it is rarely utilized. Surveys of therapists who treat children and adolescents with anxiety disorders, including OCD, have found that they rarely use exposure-based therapies,^{57,58,59} opting instead to use non-exposure forms of CBT.⁵⁷ Only 27-37% of clinicians in community mental health settings endorse routinely using exposure-based therapy with clients with anxiety-related presentations.^{60,61} Even among psychologists who correctly identified and diagnosed OCD in clinical vignettes, only half recommended ERP to their patients as the primary treatment of choice.⁴⁴

Combining medication with ERP has been found to be more effective than either treatment alone for pediatric OCD^{37,38} and is often necessary to achieve lasting relief or remission³⁶ of OCD symptoms and to restore functioning. It is recommended for patients with more severe symptoms and comorbid mental health disorders.^{30,31,32,33} Yet our study found a higher likelihood of those with pediatric OCD to receive medication only, without the standard ERP treatment. 62% of the pediatric OCD patients in the study received selective serotonin reuptake inhibitors (SSRIs) or clomipramine (the evidence-based, frontline medications proven to be effective for OCD), and only 20% also received CBT.

Taken together, our findings point to two significant gaps in the pediatric OCD care pathway: recognition and treatment. Most children with OCD may not get their OCD diagnosed or identified in clinical settings, and even among those who are identified, relatively few have documented evidence of receiving or even being referred for the gold-standard, most effective therapy for the disorder: ERP. The EHR data did not capture treatment received outside the documented care network, so it is unknown how many individuals with OCD in this sample may have been diagnosed or received treatment outside of the healthcare settings included in our EHR database. Nevertheless, our findings underscore the need for earlier recognition and accurate diagnosis of pediatric OCD, improved clinical training, and stronger pathways to evidence-based treatment such as ERP.

Many people with OCD never seek treatment,⁶² and most youth with mental health disorders do not access mental health treatment.⁶³ Children with OCD have reported numerous barriers to recovery, including inconsistent parental support, inadequate awareness in schools, social misconceptions about OCD, myths about medication, and frustration with treatment processes.⁶⁴ Yet when people do seek treatment they often have difficulty finding any clinicians who are available, let alone those who are appropriately trained and willing to use ERP. Many parents of children and adolescents with OCD have difficulty accessing effective therapy for their children's OCD, due to factors such as cost, waitlists, travel time, and lack of knowledge about exposure-based therapy, and inability to find a suitable provider who was trained to do ERP.⁶⁵

Our findings point to two significant gaps in the pediatric OCD care pathway: recognition and treatment.

Deeper diagnosis gaps exist for some.

OCD affects people of all sexes, races, and income levels at similar rates.^{20,66} Our study showed an equal distribution of diagnosed OCD across all socioeconomic statuses as measured by ADI⁴¹ but found a significant underrepresentation of children and adolescents of Color (see Table 1). We also observed trends in this data that suggests boys and male teens may be underrepresented among those identified with OCD, a finding that warrants further study.

Youth of Color. OCD is equally prevalent in Asian, Black, Latino, and White populations.⁶⁷ However, our study showed that the percentage of non-white children and adolescents — Black, Latino, and Asian — was much lower in the OCD sample than in the entire EHR database pediatric population, while white children and adolescents were overrepresented (see Table 1). This discrepancy suggests a systematic underdiagnosis of OCD in non-white pediatric populations, which is concerning and deserves further study. Our findings in the U.S. are similar to those of a U.K. study that also found severe underrepresentation of ethnic minorities with OCD in mental health services.⁶⁸ Previous studies have found that African-Americans with OCD rarely seek treatment for their OCD symptoms.⁶⁹ African-Americans and Latinos also face numerous barriers to treatment,⁷⁰ including access to mental health care.⁷¹

Race Categories	% of Overall pediatric sample (n=2.3 M unique EHR)	% of pediatric OCD sample (n=16,946)
White	68.8%	83.1%
Black or African American	21.9%	6.5%
Race not reported	0.0%	4.7%
Two or more races	2.5%	2.5%
Asian	2.9%	1.6%
Other race	3.2%	1.0%
American Indian or Alaska Native	0.6%	0.5%
Native Hawaiian or other Pacific Islander	0.2%	0.1%

Ethnicity	% of Overall pediatric sample (n=2.3 M unique EHR)	% of pediatric OCD sample (n=16,946)
Not Hispanic or Latino	88.4%	94.1%
Hispanic or Latino	11.6%	5.9%

Boys. Childhood-onset OCD occurs at a higher frequency in males than females,^{20,72,73} but our study found that the OCD patient sample in this study had significantly more girls than boys (59.9% versus 40.1%), while the overall pediatric EHR database population consisted of 54.2% females and 45.7% males. This gap is wider than the gender ratio found in epidemiological studies of pediatric OCD,^{72,73} suggesting that factors other than relative prevalence influenced the gender disparity found in this sample of children and adolescents with OCD. We believe this observation should be studied further.

Comorbid OC-Related Disorders are dramatically under-detected in youth, even by mental health clinicians.

Within the child and adolescent OCD sample in the EHR database, diagnosis rates of comorbid obsessive compulsive-related disorders (OCDs) — body dysmorphic disorder (BDD), hoarding disorder, and body-focused repetitive behaviors (BFRBs) such as excoriation disorder (skin picking) and trichotillomania (hair pulling) — were far lower than previously documented comorbidity rates in pediatric OCD populations.

- Only 0.6% of the OCD patients in our sample were diagnosed with comorbid BDD, far lower than the 10% found in prior studies.⁷⁴
- Only 0.2% were diagnosed with hoarding disorder, a small fraction of the 18-38% expected based on previous studies.^{75,76,77,78}
- Previous studies have found that 15-20% of children with OCD also have a BFRB,⁷⁹ yet only 3.5% of our pediatric OCD patient sample was diagnosed with a comorbid BFRB (trichotillomania or excoriation disorder).

Although the rate of diagnosis of comorbid OCDs was higher for OCD patients who received a mental health assessment than for those who did not, they were still far below the rates found in previous studies. These findings indicate that pediatric OCDs are dramatically under-detected in U.S. healthcare settings. Considering OCDs affect up to 1 billion people worldwide, it is clear a major gap exists. The IOCDF plans to share more findings on this topic in the future.

80% of the children and adolescents with OCD in the EHR database were also diagnosed with another anxiety disorder, including 48% diagnosed with general anxiety disorder, 15% with panic disorder, and 15% with PTSD. Comorbid mood disorders were also very common, with 58% of the pediatric OCD patients also diagnosed with major depressive disorder, and 11% with bipolar disorder. As expected, comorbid ADHD (41%), autism spectrum disorder (16%), and tic disorders (7%) were also frequently diagnosed in the pediatric OCD patients. These comorbidity rates are generally consistent with expected lifetime comorbidity rates in clinical OCD populations.^{50,51,52,53,80}

About PANS/PANDAS

Pediatric Acute Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infections (PANDAS) are related conditions. Both disorders are syndromes in which there is an abrupt onset of neuropsychiatric symptoms in a previously healthy child as a result of autoimmune dysregulation or brain inflammation that follows from an infection.⁸¹ Symptoms typically include OCD symptoms, tics, and eating disorder symptoms, but can also include ADHD symptoms, motor coordination problems, and other neurological symptoms.

Both PANDAS and PANS share multiple symptoms with other common childhood disorders, such as pediatric OCD, tic disorders, acute restrictive food intake disorder (ARFID), and anorexia nervosa. For this reason, the primary challenge in diagnosing PANS/PANDAS comes in differentiating these conditions from their related non-PANS/PANDAS conditions. Usually, it's the severity and rapidity of symptom onset and correlation with recent or current infection that are the major differentiating factors in determining if a child has PANS/PANDAS.⁸²

This white paper specifically analyzed data on pediatric OCD but did not analyze data specific to diagnosis or treatment gaps for PANS/PANDAS. The IOCDF encourages further investment and research into PANS/PANDAS. For more information about PANS/PANDAS, visit iocdf.org/about-ocd/ocd-treatment-guide/treatment-for-pans-and-pandas

Recommendations

Despite the enormous gap for diagnosis and treatment for OCD that exists today, there is hope. Children and adolescents living with OCD can thrive when given effective treatment. Early recognition, diagnosis, and evidence-based treatment can reduce symptoms, limit impairment, and improve quality of life.⁵⁶ Decision-makers from government, accrediting bodies, academic institutions, mental health professional and advocacy organizations as well as clinicians, families, and school professionals can all take action to help close the concerning gap in diagnosis and treatment revealed by this study.

1. Routinely screen all children for OCD in all pediatric and mental health settings.

In 2022, the United States Preventative Services Task Force recommended routine screening for anxiety in children and adolescents to identify undiagnosed youth who might benefit from effective treatment for anxiety disorders.⁸³ Implementation of anxiety screening in pediatric primary care settings has been found to be feasible and acceptable and significantly increased rates of diagnosis, referral, and treatment of anxiety disorders.^{84,85}

However, most anxiety screening tools do not include OCD.

Because of its prevalence and public health impact, similar routine screening for OCD should be implemented in pediatric primary care settings, which are the most common initial point of care for mental disorders in children and adolescents.^{84,86} The American Academy of Pediatrics Task Force on Mental Health has provided guidelines for general screening of behavioral and emotional problems across all age groups at well-child visits, and/or when problems are observed or reported.⁸⁷ The strategy of screening, brief intervention, and referral to treatment as needed (SBIRT) has been recommended for behavioral health problems in pediatric primary care settings⁸⁷ and should be applied for pediatric OCD.

Well validated, brief OCD screening tools for children and adolescents^{**88,89,90} exist and must be widely disseminated to all clinicians in mental health, pediatric, and primary care settings. Every child seen in clinical practice should be screened for OCD and either referred to a mental health clinician upon a positive result or provided with a comprehensive assessment.³¹

^{**}Visit iocdf.org/screener to access IOCDF's OCD screening tool.

Currently, it takes more than seven years on average for an adult diagnosed with OCD to receive treatment^{10,11,12}, and over two years for children diagnosed with OCD.^{11,13,14} However, our study found that just 0.74% of all the children and adolescents in our study were diagnosed or identified by clinicians to have OCD, well below the expected population prevalence of up to 3%. Many factors likely play a role in this issue, but helping health professionals recognize the signs of OCD and making screening tools more available can lead to earlier detection and more accurate diagnoses that get people on a path to treatment and recovery.

Scalable Solutions You Can Support:

Those in charge of decision making, policy setting, and/or compliance tracking in health settings:

- Make pediatric OCD screening tools^{88,89,90} widely available to first-line clinicians, such as pediatricians and primary care providers, as well as school professionals and mental health clinicians.
- Mandate routine screenings for OCD during assessment for any mental health disorder. Requiring screenings for children and adolescents in these settings will help uncover underlying OCD in those affected.

For everyone:

- Support funding for the dissemination of resources and tools to help school professionals to identify the signs of OCD in school children, screen effectively, and refer individuals to clinicians trained to treat it.

2. Train all mental health clinicians in how to assess, diagnose, and treat pediatric OCD.

All mental health clinicians need to be able to diagnose, assess, and treat people with OCD appropriately and effectively, yet currently very few are trained in how to do ERP or other exposure-based therapies,^{59,61,91} even though these are most effective treatments for OCD and anxiety disorders.

Most mental health graduate training programs do not currently cover OCD or ERP sufficiently⁹¹ leaving the vast majority of clinicians without the knowledge or confidence to use it effectively for pediatric OCD. While a high percentage of clinical psychology Ph.D./Psy.D. and psychiatry residency programs now require training in evidence-based psychotherapies, such as CBT with ERP, the vast majority of counseling, clinical social work, marriage and family therapy, and mental health nurse-practitioner training programs do not,⁹² and these far outnumber the psychiatry and clinical psychology doctoral programs.

Some strong OCD training programs for licensed clinicians and professional supports exist, but access and awareness remain limited.⁹² Improving both training requirements and ongoing clinical support is essential to expanding effective treatment and meeting the vast public health needs of child and adolescent OCD.

Scalable Solutions You Can Support:

Clinical mental health training programs (i.e., psychiatry, clinical psychology, clinical social work, clinical counseling, marriage and family therapy):

- Provide comprehensive training in assessment, diagnosis, and evidence-based treatment of pediatric OCD, including ERP and family-based approaches.
- Adequate training must be provided to all students, pre-licensed clinicians, and currently practicing clinicians.

Those in charge of licensure for all clinical mental health disciplines:

- Include demonstrated competency in assessment, diagnosis, and treatment of pediatric OCD as part of licensure requirements.

3. Enforce adherence to established clinical practice guidelines for pediatric OCD.

ERP has been well established as the gold standard, first-line treatment for pediatric OCD for decades.^{30,31,32} It is highly effective and can often produce lasting relief or remission of OCD symptoms. Yet, there is very low usage of ERP in clinical settings,^{57,58,59,93,94,95} despite overwhelming evidence that it is safe and effective. Studies seeking to understand why so few clinicians use ERP highlight several common reasons including a fear that exposures will upset or harm their patient, a lack of training, concerns about using standardized treatments, and the need for funding for institutions / clinics to offer more training and support the use of exposure-based therapies.^{93,94,95} One survey of clinicians who treat youth with anxiety disorders found that the top three reported barriers to using exposure-based therapies were session length, lack of training, and concern about parent reaction.⁵⁸ Therapists with more training in ERP and fewer negative beliefs about it used ERP significantly more often.⁵⁹ Therapists with psychology PhDs were more likely to use exposure-based therapies than those with master's level, social work, or counseling degrees.⁵⁷ It is imperative that all mental health clinicians follow the published, well established practice guidelines^{30,31,32,33} to either provide ERP to their pediatric OCD patients, or refer them to other clinicians who are proficient in ERP.

Scalable Solutions You Can Support:

Those in charge of clinical licensure, decision making, policy setting, and/or compliance tracking in healthcare settings:

- Enforce adherence to professional standards and treatment guidelines for pediatric OCD.^{30,31,32,33}
- Build out protocols in support of adherence that work in prescribed healthcare settings, like integrated care clinics, community mental health (e.g. CCBHCs), etc.
- Support and encourage clinicians to build their proficiency and comfort level in using ERP in their clinical practice. Resources such as case consultations, continuing education, and professional communities exist but must be utilized consistently.
- Require that all mental health clinicians receive regular continuing education about diagnosis and treatment of OCD.

4. Increase affordable access to effective care.

Barriers to accessing mental health care for children and adolescents based on affordability and health insurance coverage are substantial and must be reduced.⁸⁷ The dire shortage of mental health professionals in the U.S., especially of pediatric mental health professionals, must also be addressed. More than half (51%) of all counties in the U.S. do not have a practicing psychiatrist.⁹⁶ At least one-third of private practice psychotherapists do not accept any form of insurance and instead only treat patients who can pay out of pocket.⁹⁷

Scalable Solutions You Can Support:

Health insurance companies:

- Increase reimbursement rates for mental health clinicians.
- Reduce restrictions on the number of sessions allowed to be covered by health insurance.
- Ensure that evidence-based treatments for necessary durations and intensities (e.g. home visits, intensive treatment programs) are billable and reimbursed appropriately.

Clinical mental health training programs and government officials:

- Promote programs that incentivize an increased pediatric mental health workforce by increasing the number of graduate training slots, scholarship availability, loan forgiveness programs, mentorship opportunities, etc.
- Advocate for the adoption of interstate licensure for all clinical mental health professions, to allow for telehealth provision across state lines.

5. Provide families with the resources and education they need to actively support themselves and the individual with OCD.

Parents caring for children with OCD have clear caregiver support needs which are currently not being met, including coping with the impact of OCD on the child as well as themselves, making sense of OCD, getting help for their affected children, understanding their role as parents, and misunderstanding of OCD by both clinicians and the public.⁹⁸

Scalable Solutions You Can Support:

For mental health clinicians:

- Seek out training in gold-standard treatments for pediatric OCD, including best practices in incorporating family into care.
 - Educate yourself on treatments like Supportive Parenting for Anxious Childhood Emotions (SPACE) for scenarios in which the child refuses to take part in treatment.
 - Read the IOCDF's "[OCD Treatment Guide](#)"* to inform yourself about evidence-based therapies and medications.
- Make it part of your standard practice to provide information, resources, and support to the families of your pediatric patients, including parents/caregivers and siblings.
- Develop a list of family resources in your local community and nationally, such as support groups, community events, summer camps, etc. (The IOCDF website lists many of these.)

For parents/caregivers:

- Familiarize yourself with OCD and family accommodation, and work with your child's care team to help reduce accommodation behaviors.
- If you are not currently involved in your child's OCD treatment, advocate with your child's care team to be included.
- Connect with a local or virtual parent/family support group, and consider starting one if none are available.
- Consider Supportive Parenting for Anxious Childhood Emotions (SPACE). (See breakout, below.)

Supportive Parenting for Anxious Childhood Emotions (SPACE)

A parent-based form of therapy for childhood and adolescent OCD and related conditions. [SPACE](#) focuses on reducing a parent's accommodation of their child's symptoms, and teaching them ways to support their child while acknowledging their distress and ability to cope. It does not involve a child's participation in therapy sessions, and can be useful for helping children with OCD who may not respond to ERP.

*Please visit iocdf.org/about-ocd/ocd-treatment-guide to view our treatment guidelines, including medication dosages that are recommended for pediatric OCD treatment.

6. Raise accurate public awareness about what OCD really is.

Awareness and accurate understanding of OCD is low in the general public. A 2013 survey found that more than two-thirds of respondents could not accurately identify OCD when presented with a clear description of symptoms.⁹⁹ This lack of understanding poses a significant challenge for those struggling with OCD, making it harder for them to recognize their condition, seek support, and access the life-changing treatment they need. The term “OCD” has become a common cultural catchphrase referring to quirks or preferences around cleanliness and orderliness. This casual misuse obscures the reality of OCD as a serious mental health condition.

Misinformation about OCD is rampant. A recent study of OCD-related video content on a social media platform found that only 18% of them contained accurate information, while 29% were misleading.¹⁰⁰ Health care providers were underrepresented among content creators, with most videos coming from non-professional sources. Stereotype-driven videos were more frequently viewed and liked than those that provide accurate information about OCD.¹⁰¹

Without increased awareness and understanding, stigma against people with OCD and barriers to treatment will persist. Insufficient mental health literacy and fear of stigma and discrimination are particularly important barriers to care for racial and ethnic minority individuals with OCD^{70,101} and their parents.¹⁰² However, initiatives such as information packs and webinars aimed at increasing parents’ knowledge about OCD have been successful.¹⁰³ Information stalls and teaching events have also been found to significantly increase knowledge of OCD in minority youth.¹⁰⁴ We recommend continuing initiatives to increase awareness and accurate understanding of OCD for the general public, policymakers, educators, and clinicians.

Scalable Solutions You Can Support:

For everyone:

- Share the data in this white paper.
- Share your OCD story. OCD affects millions of Americans, but too many suffer in silence. Courageous individuals who speak openly about their lived experience of and treatment for OCD help bring hope and healing to many others.
- Speak up about OCD as a recognized topic/area of importance for workplace and school*** mental health initiatives.
- Advocate for your local, state, and federal governments to recognize OCD Awareness Week in October.
- Increase awareness by disseminating information to legislators and policy makers, conducting public service announcements, sharing social media posts, engaging in awareness and fundraising campaigns, and working with local and regional advocates and volunteers.

***Anxiety in the Classroom is an IOCDF initiative that helps students, parents/caregivers, and school staff recognize signs of anxiety and OCD in classroom settings. Learn more at anxietyintheclassroom.org

MYTH: WE ARE ALL “A LITTLE BIT OCD” AT TIMES.

FACT: OCD is not a personality quirk or a character trait — it is a very real mental health condition that affects about 8 million adults and 2 million youth in the U.S. alone. While many people can have obsessive or compulsive traits, OCD stands for obsessive compulsive disorder, and people who are diagnosed with OCD cannot simply “turn it off.” Research has shown that their brains are wired differently than the brains of people without OCD, and as such OCD strongly influences their thoughts and actions.

MYTH: OCD IS NOT THAT BIG A DEAL, PEOPLE JUST NEED TO RELAX AND NOT WORRY SO MUCH.

FACT: Having OCD is not simply an overreaction to the stresses of life. While stressful situations can make things worse for people with OCD, they do not cause OCD. People with OCD face severe, often debilitating anxiety over any number of things, called “obsessions.” This level of extreme worry and fear can be so overwhelming that it gets in the way of their ability to function. To try to overcome this anxiety, people with OCD use “compulsions” or rituals, which are specific actions or behaviors. These compulsions are not activities a person with OCD does because they want to, but rather because they feel they have to in order to ease their fears. OCD is not about logic — it is about anxiety and trying to get relief from that anxiety.

MYTH: OCD IS JUST ABOUT HAND-WASHING, CLEANING, AND BEING NEAT.

FACT: Triggers related to cleanliness and symptoms related to washing make up only a small part of the range of OCD triggers and symptoms. People with OCD can have obsessions related to a wide variety of things, including losing control, hurting others, unwanted sexual thoughts, and many more. Similarly, the anxiety caused by these obsessions can be lessened by different compulsions, such as “checking” (e.g., re-checking door locks, repeatedly making sure the oven is off), “repeating” (e.g., doing the same action or ritual over and over to be sure it was done “correctly”), and “counting” (e.g., doing things in certain numbers, counting items to certain numbers).

MYTH: PEOPLE WITH OCD ARE JUST “WEIRD,” “NEUROTIC,” OR “CRAZY” AND THERE IS NO HOPE FOR THEM TO EVER LEAD HAPPY, FUNCTIONAL LIVES.

FACT: With proper treatment, it is very possible for people with OCD to lead full and productive lives. Many people respond positively to behavioral therapy and/or medication. Specifically, Exposure and Response Prevention or ERP is considered the first-line treatment for OCD. Additionally, medication (such as anti-depressants like SSRIs) may also be recommended for people with OCD. Family therapy can also be very beneficial since family members (including parents, siblings, and spouses) often play a major role in recovery. Finally, many individuals report that support groups are very helpful. Support groups provide a safe, understanding place for people with OCD to feel less alone, as well as to teach and learn from their peers. People with OCD use one or several of these options to help them manage their OCD, as well as the support and understanding of their loved ones.

7. Equip educators and school professionals to recognize OCD and connect students with support.

Misunderstanding, stigma, and failure to identify OCD in classroom settings are particularly important barriers for children and adolescents with OCD. One study of primary and secondary school teachers found that most of the teachers identified the contamination- and order-related OCD symptoms described in a vignette as specific to OCD and would recommend talking about the problem and seeking help. However, only a few knew about the most effective OCD treatments or identified compulsions as a main OCD symptom. Moreover, only about half of the teachers correctly identified OCD's possible interference in classroom routines, such as delays to achieve perfection or concentration problems, and strategies for dealing with OCD, such as continuing with the class rhythm. Educating teachers about OCD and how to identify it in students is critically important and can be done in various ways. A recent study found that providing a brief educational intervention to teachers significantly improved their knowledge and attitudes about OCD and reduced stigma.¹⁰⁵

Scalable Solutions You Can Support:

For school administrators:

- Designate annual professional development focus on mental health topics.
- Ensure the inclusion of OCD and related disorders in any social-emotional learning (SEL) initiatives.
- Require that all school behavioral health staff in your district know how to recognize and work with OCD and related disorders.

For school mental health staff:

- Educate yourself on OCD and related disorders and how they show up in schools and impact academic performance.
 - Advocate for your discipline's professional organization to prioritize OCD and related disorders as a key competency area for your profession.
- Provide support and consultation to your school-based colleagues on working with students with OCD and related disorders.
- Support administrators in developing your school's protocol for addressing OCD and related disorders.
 - Include families in building out these supports and protocols.
- Familiarize yourself with external referrals and resources in your community, including your students' families.

For everyone:

- Advocate with schools in your district for the inclusion of OCD and related disorders in their mental health education.
- Leverage parent-teacher association (PTA) organizations to engage parents and caregivers as collaborators in engaging and educating school districts on OCD and related disorders.

Conclusion

The findings in this white paper show that gaps in diagnosis and treatment begin early for children and adolescents with OCD. Too many are going unrecognized or without appropriate treatment during a critical period in their development. For many children, this can mean years of suffering from OCD without knowing what is wrong or getting treatment that can help. During that time, OCD can become more severe and significantly interfere with school, relationships, family life, and long-term mental health.

These findings represent systemic gaps, not inevitable outcomes. Our findings point to concrete opportunities to identify OCD sooner, improve access to effective treatment, and prevent years of unnecessary suffering.

The IOCDF is already investing significant resources in these priorities through our [Vision 2030](#) strategy, working to improve early identification, expand access to effective treatment, and strengthen support for children and families. But we cannot close these gaps alone. We need families, health professionals, educators, policymakers, and the public to join us in making sure more children with OCD are recognized and get the care they need.

How You Can Help

- Share the findings from this pediatric white paper with healthcare providers, educators, and policymakers.
- Learn to recognize the signs of OCD in children and adolescents.
- Donate to support the IOCDF's work to improve training, awareness, research, and access to evidence-based treatment.

OCD is treatable. The sooner we recognize it, the sooner children can get the care they need. Together, we can help more children spend less of their childhood struggling with OCD and more of it being kids.

"Throughout my childhood years combating OCD, I was truly fortunate enough to have parents that caught onto the signs early on and got me proper help. While growing up and becoming more mature and educated, OCD themes tend to change to latch onto what is most prominent in your life in a certain moment. Finding the right OCD therapist that can pivot when themes change and provide research-based and effective OCD treatment modalities, such as Exposure and Response Prevention (ERP), is crucial to understanding and combating the intricacies of OCD. Because I received effective support from several therapists at an early age, I came to understand that OCD is ego-dystonic, meaning it causes intrusive thoughts and obsessions that conflict with a person's true values, morals, and sense of self."

– Julia Hyman



Key Terms

Cognitive-Behavioral Therapy (CBT): A form of therapy that focuses on addressing the ways we think and behave. Exposure with response prevention (ERP) is the specific type of CBT that is the gold standard evidence-based therapy for OCD. Other forms of CBT may have differential efficacy relative to ERP.

Comorbidity / Comorbid (“Co-occurring”) Disorder(s): Having more than one condition or being diagnosed with more than one disease/disorder. It means that both conditions exist and may interact within the same person at the same time. Comorbidity is the rule, not the exception.

Electronic health record (EHR): Electronically stored medical and health information from visits to medical centers, clinicians, hospitals, and other healthcare settings.

Exposure and response prevention (ERP): ERP is a type of CBT which involves having a person with OCD intentionally trigger an obsession through an “exposure” activity, and then resist the urge to engage in compulsions (“response prevention”). This causes an initial burst of anxiety, but gradually, there is a natural decrease in that anxiety, called habituation. Repeated exposures eventually extinguish obsessional fears, eliminate compulsions and avoidance behaviors, and promote learning. ERP assignments usually proceed along a hierarchy of progressively more distressing exposures. ERP is initially done with a therapist, who develops the ERP hierarchy and guides the person with OCD through their ERP assignments. Eventually the person with OCD becomes more able to resist rituals on their own. ERP is considered a first-line treatment for OCD, something to try first when beginning an OCD treatment journey.

Selective serotonin reuptake inhibitor (SSRI): A class of medication that works by blocking the reabsorption of serotonin, a neurotransmitter, from the synapse. SSRIs are the first-line, evidence-based medication treatments for OCD.

Obsessive Compulsive Disorder (OCD): A disorder of the brain and behavior, causing distress and impairment in those affected. OCD involves both obsessions and compulsions that take a lot of time and get in the way of important activities the person values. People diagnosed with OCD experience repetitive, intrusive thoughts or fears that cause anxiety or distress. They try to reduce the distress caused by their obsessions by doing compulsive behaviors (rituals) or avoidance.

Obsessive Compulsive-Related Disorders: A category of mental health disorders that are related to OCD, as described in the DSM-5. These include body dysmorphic disorder (BDD), hoarding disorder (HD), and the body-focused repetitive behaviors (BFRBs) of skin picking (excoriation) and hair pulling (trichotillomania). Tic Disorders and Tourette Syndrome and certain Eating Disorders are also strongly related to OCD.

Prevalence: The sample analyzed in this paper covers the 10-year timeframe between 2015 and 2025. Comparisons made to other prevalence rates are lifetime prevalence rates (the percentage of cases in a population with a particular condition/disorder at any point in their lifetime).

Supportive Parenting for Anxious Childhood Emotions (SPACE): A parent-based form of therapy for childhood and adolescent OCD and related conditions. SPACE focuses on reducing a parent’s accommodation of their child’s symptoms, and teaching them ways to support their child while acknowledging their distress and ability to cope. It does not involve a child’s participation in therapy sessions, and can be useful for helping children with OCD who may not respond to ERP.

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IOCDF Support for Kids, Teens, Families, and Clinicians

IOCDF Kids Site

A resource for professionals on diagnosing and treating pediatric OCD and PANDAS/PANS using evidence-based treatment methods. kids.iocdf.org

Online OCD Camp

A virtual event for kids and teens with OCD and their families, featuring interactive sessions and activities for elementary, middle, and high school students. iocdf.org/camp

Anxiety in the Classroom

An online resource center for school personnel, students, and their families. anxietyintheclassroom.org

“Supporting Our Families” Livestream

A monthly livestream for parents and caregivers raising children with OCD, featuring expert guidance, practical strategies, and community support. kids.iocdf.org/supporting-our-families-livestream

Pediatric BTTI Training

An intensive training for mental health professionals who treat children and adolescents with OCD and related disorders. iocdf.org/btti



Our Mission

The mission of the IOCDF is to ensure that no one affected by OCD and related disorders suffers alone. Our community provides help, healing, and hope.

Our Vision

Our vision is that everyone impacted by OCD and related disorders has immediate access to effective treatment and support.

Make a difference. Donate to the International OCD Foundation at iocdf.org/donate.

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