TEAM UP SCALING & SUSTAINABILITY CENTER™

# Case Study

# Shared Decision Making in Care for Attention Deficit and Hyperactivity Disorder in Children

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# Case Study

## Initial Visit

In January 2021, Miguel, a 10-year-old Latinx boy, attended his first physical exam since the COVID-19 Pandemic. I met his family 5 years ago when they arrived from the Dominican Republic with Miguel and his sisters. He lives with his mother and father and two sisters, 15 and 5 years old. While his parents speak only Spanish, he and his siblings are now bilingual. Our onsite interpreter, Maria, knows the family well and was able to join our session.

The family shared the following updates: Miguel's grandfather died from COVID-19. The family is struggling financially, and they are very worried about Miguel's performance at school.

Miguel, a fourth grader, has been having difficulty in class. His teacher, Ms. Bright, recently called the family with concerns about the quality of his work and difficulty with turning in his assignments. Ms. Bright noted that he is often out of his seat, particularly during writing assignments, and is easily distracted by other children. She reported that Miguel is not rude but has a difficult time following directions. Ms. Bright felt that he could be a good student but does not put in his best effort. She also noticed that he does not seem to have fun at recess.

During his physical exam, Miguel said that he was initially happy to be back at school and see his friends in class. He also commented that he does not like playing outside with the 'big kids' who laugh at him when he plays basketball. He is upset and confused that the teacher yells at him and blames him for things he did not do. He admitted that he comes home from school feeling 'grumpy.'

Miguel's parents said that they did not like the teacher as she had not taken the time to understand him or his family. They were frustrated that the teacher did not contact them until December about her concerns and sent them a letter in English.

In our pediatric practice, we screen all children for risk of psychosocial and behavioral problems as recommended by the American Academy of Pediatrics (AAP) and required by the Commonwealth of Massachusetts.[1,2] Miguel's mother completed the Pediatric Symptom Checklist-17 (PSC) in Spanish.[3,4,*] Miguel's total score was 16 and his attention subscale was 9, indicating a higher risk for psychological problems with specific difficulties in paying attention.

I explained the findings of the PSC to Miguel and his family. The scale indicated he had behaviors seen in children with Attention Deficit Hyperactivity Disorder (ADHD) as well as some symptoms of low mood and increased anxiety. To understand more about the meaning of his score, we would need more information from the school and the family. Further, to diagnose ADHD, there must be reports of difficulties with inattention and/or hyperactivity in at least two settings (e.g., school and home).[5]

Fortunately, our pediatric practice includes an integrated behavioral health (IBH) team comprised of behavioral health clinicians (BHCs) and family partners (FPs). The FPs, trained as community health workers with a focus on developmental and behavioral concerns, connect with the family, provide support and psychoeducation, and coordinate services with the school and other outside agencies. The BHCs provide clinical assessment and interventions as indicated for the child and family. With the help of the interpreter, Miguel's family agreed to meet with Lina, our Spanish-speaking FP, about their concerns for Miguel at school.

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* The PSC is a broadband behavioral screening instrument that assesses three separate psychosocial domains: internalizing, externalizing, and attention. The PSC is commonly used in pediatric primary care clinics to support the identification of behavioral health concerns. The total score can indicate general behavioral health concerns and subdomains can be individually scored to assess each domain.[4]

In alignment with our pediatric ADHD workflow, Lina and I asked the parents to complete consent forms to communicate with the school staff. Lina met with the family alone to complete the Spanish language version of the National Institute for Children's Health Quality's Vanderbilt ADHD Assessment Scale, a standardized tool to specifically assess for symptoms of ADHD.[6] The family also gave permission for Lina to send a Teacher's Vanderbilt ADHD Assessment Scale to Ms. Bright. The Teacher's Vanderbilt includes a survey of the presence (or absence) of symptoms of inattention, hyperactivity, oppositional behavior and emotional distress as well as school performance measures.[6]

The parents privately told Lina that they were disappointed in Miguel's behavior, noting he was acting up in school "just to get attention" as he did at home. His mother also worried about the school's perception of them as parents for having such a difficult child. His mother became teary and spoke about an older cousin who was "just like Miguel" and ended up in jail. As parents, they were also very frustrated with the lack of timely communication from the teacher. They confided that they felt responsible and embarrassed that they did not notice the issues.

## Diagnosing ADHD

Two weeks later, Miguel and his family met with me in the office. Lina was able to collect the completed Vanderbilt Scales from the teacher and the parents. Ms. Bright reported significant hyperactivity and inattention as well as mild oppositional behavior. Although frustrated with him, she noted that "he is trying hard" and sometimes seems "a bit sad." Miguel is performing below grade-level in reading, which she attributes to his dual language capacity. She also commented that his parents should be "more involved." The parents similarly noted that he has difficulty staying organized and following directions. He does not try to disobey his parents but often "forgets" to do his chores including cleaning his room. They have noticed even when watching a video, he is unable to remain still.

Lina and I discussed the results of the assessments together with the family. The Vanderbilt Scales from the two sources (home and school) indicated that Miguel had significant struggles with focusing, staying organized, and paying attention, and he meets criteria for ADHD. I further explained that children who have difficulty reading and/or have worries about their family can have difficulty focusing. These are areas of concern that can be explored by our IBH team and the school over time.

Lina has worked with many families with children struggling in school, including her own. She was able to translate our medical discussion into lay terms and add her own words of support and education to the conversation. The parents easily connected with Lina as they talked about their life in the Dominican Republic.

## Plan of Care

Together we discussed the next steps, focusing on evidence-based options for interventions for ADHD. The AAP recommends medications and behavioral intervention at school and at home.[5] We talked about the ways schools can help children with ADHD and how parents can help to manage difficult behaviors. I provided information about methylphenidate, a Federal Drug Administration approved medication for ADHD, as an option to treat his symptoms.

In addition to Lina's engagement with the family, I provided psychoeducation. Miguel's family felt he could learn to control his behavior, that the problem was not medical in nature and did not warrant medications.They were most concerned about his reading and felt the school had not provided academic support for their son. They appreciated Lina's contributions and agreed to arrange a school meeting to discuss the diagnosis and additional academic testing and support.

I listened carefully to the family and understood that their primary goal was to work on his behavior and increase academic support. I wrote a letter to the school to confirm Miguel's diagnosis of

ADHD and suggested classroom accommodations for the creation of a 504 plan† as well as recommendations for further educational and psychological testing. The parents, with much encouragement, planned to share this with the school. They also agreed to a referral for a Spanish speaking in-home therapist in addition to a follow up appointment with our BHC, Sandra. Given that there is often a 2-3 month wait for in-home therapy, Sandra will provide 'bridge' support until the in-home team is able to start. Sandra, with the help of our interpreter, Maria, will meet with Miguel and his family to further assess the concerns around anxiety and depression. Sandra will also begin to provide behavior management training to his parents and communicate her observations to the school.‡ We explained this process to Miguel and his family.

## Follow-up Visit

I saw Miguel two months later via a telehealth visit, using an online interpreter. I followed Lina and Sandra's work with the family via the electronic health record. Lina worked closely with the family and scheduled several visits to provide support, psychoeducation and attend a school meeting. She reminded the school that all communications, including reports, must be translated into Spanish and that a Spanish interpreter is required to be present for school meetings. Sandra was able to meet with Miguel and teach some coping skills. She also worked with the family to help put more structure and limits in place for his time at home. The family shared other stresses and worries they were experiencing.

In addition, Lina made referrals for much needed family resources and in-home therapeutic support. The school agreed to provide Miguel with a 504 plan as well as schedule a full educational evaluation. During the meeting, the school strongly encouraged the parents to speak with their doctor about starting ADHD medications. The parents were clear they did not want medication at this time. Lina assured the family that the school cannot require a child to take this type of medication.

The family felt very supported by Lina and Sandra. Miguel's family continued to work with them while waiting for the in-home therapy team. Miguel's parents reiterated that they were not interested in discussing medication at this time but agreed to revisit this at our next visit in 2 months.

## Three Months Later

Miguel and his family attended a follow-up visit with me in June. Miguel was doing a bit better. The school provided support for him in the class, including sitting in the front of the room and breaks when needed. The school completed an educational assessment, and he was diagnosed with a learning disability in reading for which he was receiving specialized teaching. His baseline inattention and hyperactivity had not changed but his parents had learned core parent management strategies from Sandra. Lina continued to check in with the family on a regular basis to connect them to financial resources and to check-in on the in-home therapy referral. Lina and I met with the family to discuss the option and possible benefits of medications. The family said they would consider this option in September after he started his new school year.

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† In Massachusetts, a child may be eligible for accommodations under a 504 Plan if they have a physical or mental health disability that limits one or more major life functions. A 504 Plan is supported by the federal civil rights law, Section 504 of the Rehabilitation Act of 1973.

‡ Parent management training is a type of therapy where parents learn skills to provide structure for their child while providing positive reinforcements and consistent consequences for negative behaviors. The intervention often includes family activities and homework to practice new parenting skills.

# Clinician Perspective

## Protocols Versus Conversations: Finding Family Voice in Shared Decision Making

The experience of Miguel and his family represents the complexities of assessing school-aged children for ADHD. In this case study, the assessment process began with the PSC. Beyond the score itself, the results of the screening tool started a conversation with Miguel's parents about the challenges he was facing. Without this dialogue, the degree of Miguel's difficulties may have gone unnoticed. More generally, reviewing PSC results with families provides the opportunity to discuss normal development and social emotional issues in the context of a regular checkup even if the scores are below the positive threshold score.

Identifying and diagnosing ADHD can appear to be a straightforward process. Primary care providers (PCPs) have access to evidence based guidelines from the Centers for Disease Control and Prevention, American Academy of Child and Adolescent Psychiatry, and the AAP.[5,8–10] There are a variety of reputable resources with clear guidelines and/or algorithms to support the diagnosis and interventions for ADHD, including recommendations to assess for conditions that can mimic ADHD such as depression, anxiety, learning difficulties, and stressful life events.[5,8–11]

Practice guidelines also emphasize the essential role of parents and community-based providers in the diagnostic decision-making process. AAP ADHD guidelines, for example, recommend meeting with the family and patient to discuss treatment options and outline medications as the first-line treatment, along with classroom interventions and/or parent management behavioral training.[5,11,12] ADHD medications, specifically stimulants, are among the safest and most efficacious of all psychiatric medications.[5] Nonetheless, many families worry about the use of psychiatric medications in children. Specifically, families express concerns about how medications will change their child, impact their growth, or that they may become 'addicted' to the medications.[5,10,13] In addition, medication prescription and management is not always equitably available to all patients. Peer-reviewed publications have documented less frequent use of medications in non-white families as well as qualitative studies about how medication use varies among racial and ethnic groups.[5,10,14]

Evidence suggests integrated and collaborative care models are effective in managing and treating ADHD.[15–17] The TEAM UP Model™ has demonstrated the importance of FPs, BHCs, and PCPs working as a team to engage families around the assessment and treatment for developmental and behavioral health concerns seen in primary care. Specific to ADHD, the team-based approach is key to achieving the complementary goals of providing evidence-based assessment, diagnosis, treatment (both behavioral and pharmacological), and the incorporation of family-voice in treatment decisions.[5,11] TEAM UP trains FPs in modalities such as Motivational Interviewing that facilitate open discussion to encourage families to voice their experiences and advocate for themselves and their children. In addition, FPs receive training in the fundamentals of child development and behavioral health. FPs connect with families by speaking the same language, sharing a cultural background, and/or by sharing their own lived experience. In this way, FPs often function as cultural brokers, translating the experience of the family to the IBH team, as well as empowering the family to make informed choices and advocate for their children. Over time, our primary care providers have come to understand that FPs are essential to the IBH team to incorporate the family's voice into treatment planning conversations.

### Practice Transformation and Practice Transformed: Managing the Impact of COVID-19

Miguel's story occurred at a very particular time in our history. His difficulties came to the attention of his parents and providers in the middle of the COVID-19 Pandemic. The pandemic affected families in a multitude of ways, including illness, loss of family members, and social isolation. Remote or hybrid learning was particularly difficult for children with attention problems and/or learning challenges.[18] The rates of mental health concerns dramatically increased in all populations but particularly in minority and less resourced populations, highlighting already existing health disparities.[19–21] This was the case for Miguel.

Our community health center (CHC) introduced the TEAM UP model in 2020, just as the COVID-19 Pandemic began. Our IBH team was interviewed, hired, and trained during this time, meaning that the group had little opportunity to work as a team with each other or the primary care pediatric staff (PCPs, Medical Assistants, Nurses). As a result, we created virtual opportunities for all members of the team, including PCPs, to meet. We started a series of weekly virtual meetings for case consultation, teaching, and mutual support. Within a few months, our CHC returned to in-person visits for primary care. With this shift, the IBH team established an on-site system for warm hand offs where a member of the IBH team met with children and families at the time of their visit with the PCP. This model of care led to a more cohesive team, fewer professional and hierarchical barriers, and increased opportunities for the family and the IBH team to connect in person during their routine health care visits.

The COVID-19 Pandemic forced the health care system to be creative about ways to deliver care. In the early days of the pandemic, we shifted to telehealth and video visits, offering an alternative way to interact with families in primary care and behavioral health. For busy PCPs managing children with ADHD, telehealth has continued to be a great option for following up more frequently and improved convenience of appointments to provide therapy, track school progress, and monitor medications. TEAM UP data has shown that telehealth is not perfect. Initially thought to help solve some of the barriers to accessing services, TEAM UP data collection has shown that telehealth can be a challenge for non-English speaking families.[7] However, in our CHC, for those who could access the technology, we found that families appreciated the opportunity to meet via telehealth as an alternative to monthly, in-person office visits. Accordingly, TEAM UP data showcased that Vietnamese speaking patients at our CHC were more likely to have a telehealth visit compared to the average patient across all CHCs implementing the TEAM UP model.[7] Telehealth increased access to real-time collaboration for the broader care team, including community therapists, patient advocates, FPs, schoolteachers, and interpreters. Families have expressed their appreciation that all providers can easily meet with them at the same time.

## Conclusions and Lessons Learned

ADHD, classified in the Diagnostic and Statistical Manual, 5th Edition as a Neurodevelopmental Disorder, is a lifelong disorder presenting in early childhood before the age of 12.[22] While ADHD is relatively common in the pediatric patient population, inattention and hyperactivity are symptoms of many other childhood medical and psychiatric conditions. A comprehensive diagnostic process is required to fully understand the child's symptoms, their family, and the child's functioning in school and home environments. Ultimately, a clinical diagnosis for ADHD includes formal and informal input from families and schools, as well as the expertise of the IBH team.

Understanding the complexities of ADHD is particularly important for the communities served by TEAM UP CHCs. We know that ADHD is both under- and over-diagnosed in structurally marginalized and underserved populations.[23–25] Children of color are more likely to be diagnosed with disruptive behavior, such as Oppositional Defiant Disorder, instead of ADHD or another learning disability.[26]

Evidence also suggests that children of color may be more at risk for ADHD but less likely to receive intervention.[23,27] Similar trends have been found through TEAM UP data collection and have been summarized in the TEAM UP for Equity: Use of Data on Race, Ethnicity, and Language to Improve Equity in Behavioral Healthcare report.[7]

Our clinical practice for the assessment and intervention of ADHD was clearly transformed by the implementation of the TEAM UP model and the activities of the IBH team. This was true for most of the CHCs partnered with TEAM UP. The Cohort 2 Report Synopsis details findings of the ADHD Chart Abstraction Project that explored the effect of TEAM UP practice transformation on the identification and care for children newly diagnosed with ADHD. The data largely suggests that FPs contributed to the gathering and management of of completed Vanderbilts, which is often a challenging task without additional support.[7]

It is also important to highlight that PCPs rarely complete assessment, diagnosis, and treatment of ADHD in one visit; rather, there are multiple visits and conversations between and among the IBH team and the family. While guidelines are essential to evidence-based practice, trusting relationships with the child and family, built over time, are key to providing comprehensive clinical care. Through the implementation of the TEAM UP model, we have had the opportunity to transform our pediatric practice to include FPs and BHCs in the care of children with developmental and behavioral health concerns.

## In Summary

1. PCPs are well positioned to evaluate children with behavioral health concerns given the long-term relationship with both the child and the family.
2. The TEAM UP model of IBH care supports the PCP and the family in better understanding the concerns of the child and the family.
3. FPs are key to connecting families to community support and empowering them with information to make the best decisions for their children. All parents want their children to be successful at school and appreciate the multifaceted approach to support that FPs provide.
4. Cultural biases exist in health care and in educational systems that may affect how behavioral health concerns in children are perceived.
5. All families with children diagnosed with ADHD should receive information about evidence-based interventions including parent management training and medications if over 4-years-old. Medications should not be the beginning nor the end of interventions. The TEAM UP model and the IBH team offer the opportunity for families to have a voice in the health care of their child.

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