

The importance of a parent community for support.

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Raising a child with mental health challenges is often an isolating and overwhelming experience for the parents or caretakers of that child. Finding the answers for assistance and the pathways toward resources can be grueling, taking hours of work and energy. I experienced this firsthand with my now 18-year-old daughter who has struggled with her mental health since she was 7 years old.

Although I had earned an advanced degree in Counseling and had spent several years doing crisis intervention with university students, I realized that the type of resilience needed as I cared for my own child in crisis was completely different. The hurdles I needed to overcome as I sought out assistance for her seemed never-ending. Back at the beginning of my journey in 2012, when there were signs that my daughter needed therapeutic support, it took 17 phone calls to find a children's therapist who was taking new clients and then another 10 calls to find a psychiatrist when it became apparent that her treatment required medication. My husband and I were worn out and overwhelmed when the psychiatrist diagnosed my daughter with obsessive compulsive disorder (OCD). Luckily, I learned that the International OCD Foundation's conference was being held nearby for people and families of children with OCD. Attending that conference helped me to feel less alone in our family's struggles. Sessions and social events for parents of children with OCD were built into the conference program. Suddenly my husband and I were able to have open conversations about our challenges and learn about types of therapy and medication that contributed to successful treatment. My daughter saw that she was not the only one struggling and my son connected with other siblings in families and learned techniques to help him interact better with his sister. With the resources, encouragement and support I gained, I was able to find a local, effective children's center where

my husband, my daughter and I could work to learn the CBT skills needed to treat her OCD and keep it at bay.

Years later, when our daughter's depression entered the picture, our hope started to wane again. We couldn't find the right medications to help, even though her psychiatrist had attempted over 15 different combinations. We were overcome with shock when suicidal ideation became part of the equation and knew she needed to be treated on an inpatient basis, but there was no guidance on how or where to go. I reached out to another local parent who I knew worked in the mental health field. She not only gave me guidance but accompanied my daughter and I to the inpatient facility and stayed with me during the difficult intake process. It was a heart wrenching experience to leave my 14-year-old at a mental health hospital, and I don't know how I would have been able to do this without another parent's help. I promised myself that at some point in the future I would give another parent the same support.

There were three 60-minute seminars on parenting skills during my daughter's next two inpatient stays which were informative but did not allow for any interaction with other parents. My sense of isolation and stress grew as I tried to navigate her lack of progress in school, how much to share of her story with friends and family and finding any future care she might need. Luckily the town board of health offered a few programs about mental health where I was able to connect with other parents who shared information which helped me design a road-map for the accommodations and academic support my daughter needed. This advocating took off some of the pressure I was feeling at the time, and it empowered me take the necessary steps my daughter needed as she reacclimated into school.

During 2021 and COVID my daughter was diagnosed with a chronic illness, and immediately

taken off the psychiatric medications she had been on, for fear that it was contributing to her physical symptoms. She immediately went into a bout of deep depression where every day was a struggle to persuade her to stay alive. All mental health hospitals and floors were filled over capacity. Her suicidal ideation grew, and at home we put all our energy into trying to keep her alive. My husband and I sought a couple's therapist to help guide us to work together, but the anxiety and exhaustion we felt day after day was unbelievable. There were no other parents to connect with in-person, so I went to Facebook and found a helpful group for parents of children with mental health issues in my state.

Suddenly I could reach out and ask questions since it was a private group. It was awkward, but through group posts, I learned that there were ways to find out which facilities had the lowest wait times. This often ranged from 6-12 weeks at the time, with children waiting in chairs in ERs or on gurneys in hospital hallways. My daughter's mental illness ran our household due to the accommodations my husband and I felt forced to make. We re-entered the stage of isolation as we were stretched thin trying to meet our professional and family responsibilities. My search for assistance with my daughter continued as I watched her lose hope in getting any relief. I put her on a three-month waitlist for a partial hospitalization program (PHP) for depression and OCD at a hospital I had read about online in a nearby state. As we inched closer to the start date, she limped through her remaining days of the school year. My fatigue grew with trying to get her out of bed each morning, and my negotiating skills were put to the test as I tried to work with her school to find nonexistent accommodations, offering her sufficient support.

Had it not been for the parents I spoke with through connections born on the parent Facebook group, I may have lost complete hope when our daughter's long-awaited outpatient program had to unexpectedly defer new patients to an unknown date due to construction issues. I knew from my communication that other parents had faced even more challenging situations, but my heart was breaking as I watched my child's desire to live in such pain fade. At that point the waitlists at most Boston area hospi-

tals were down to two weeks and with the help of her psychiatrist, we were able to get her a bed within a couple days of arriving in an ER.

Three difficult months went by with her sitting inpatient where we were unable to find a step-down program. Due to COVID regulations, we were only allowed to see and communicate with her once a week. Her depression grew and she began to self-harm at any point possible. During that time, I found myself trying to research every avenue to find a better spot for her, to no avail. Finally the deferral for the PHP for depression and OCD came through with a start date, but due to the distance from our home and my daughter's physical and mental state, she would not be able to make the daily 3-hour commute. We decided that the most effective option was for she and I to stay in a hotel near the hospital. Unfortunately, this PHP program did not connect the participants' parents in any way. It was clear though that our daughter might still need more support, and another step might be necessary before we could bring her home. At her psychologist's urging, I put her on a waitlist for a couple of residential programs. We also hired an educational consultant to guide us through the process. The greatest support I found at this point was again in a Facebook group for parents of children searching for mental health residential programs.

Another helpful form of support was the weekly, three-hour DBT training my husband and I participated in online. There were 10 participants in the 14-week Family Connections program and six couples in the 16-week IOP program we attended. It was nice to know we weren't alone in our struggles with our daughter, but neither program had much social interaction for support or resource sharing for future needs. A few months later, I joined a free, virtual 6-week program for parents of young adults with mental health needs out of Boston University called Flourishing Families. Participants shared their own experiences in breakout groups as we practiced therapeutic coping skills we were learning to use for ourselves to give us more strength and resilience as we made our way through the daily challenges of having a family member with mental illness. Local resources were also shared which added to the won-

derful support that this well thought out program offered. In addition, each member of the group had the opportunity to meet with one of the group facilitators individually each week during the program. Individual goals for self-care were established and implemented during those sessions.

I used the Flourishing Families program as a model when I decided to create a support group in my town for parents of children struggling with mental health. I wanted to prevent parents from feeling that sense of isolation and hopelessness that I once felt. The board of health and the town manager were open to sponsoring the group when it became apparent that more assistance was needed for families in our town. I have been able to co-facilitate the monthly group with two newly hired Community Wellness Coordinators. Parents attend and we begin each session with a mindfulness activity. I then share a DBT skill with the parents that they might use with their child. This is followed by conversations around support that members might need. We complete the 90-minute drop-in sessions by sharing resources for the parents on mental health supports both online and in our community. Facilitating this group has opened the door to others who are parenting a child with mental health challenges to seek me out individually as well. It never surprises me to receive a text or phone call from a parent searching for resources for their child.

When my daughter moved to the long-term residential program, it was a much better fit. She was able to catch up on the school she missed and graduate from high school. She learned leadership skills and was a member of a close community of girls which assisted her with her social skills. One of the best aspects of this 18-month program has been the family-centered model they prioritize. We have family therapy once a week, have therapeutic family and parent weekends every two months, with support groups built into the schedule. Her residential treatment center also holds virtual parent meetings twice a month. The mothers of the students have established a chat group with all of us chiming in often on parenting topics. These activities have facilitated communication among us outside of scheduled events. Many of the friendships I have formed continue long after the students may have completed the program. There were many times that I struggled to keep my head above water as I tried to navigate the challenges I faced with our daughter. Knowing that my situation was not an isolated experience and that there were other parents dealing with similar issues gave me the strength and encouragement that I needed to make decisions and seek the necessary assistance during each stage of my experience as a parent of a child struggling with her mental health.