

Story *of* TRIUMPH



When my daughter was sixteen years old, the only option she could grasp to pull herself from her pain was death; her story is one of triumph.

In 2011, I was not an expert on the children's mental health system, and I am still not. I am simply a mom who struggled through what felt like a labyrinth of mirrors to access the behavioral health services that would save my daughter's life.

At sixteen years old, she'd already been struggling for several years and suffering more deeply than she revealed. In 5th grade, social anxiety was becoming problematic for her and by middle school, she was cutting herself to relieve the pain that overwhelmed her. On one hand, she was entering her adolescent years with great strengths – she had a joyful sense of humor, held close friendships, and enjoyed great talent in her chosen activities: music, theater, and horses. Academically, she tested above expectations for her grade and was well-liked by her teachers. Although she was successful in showing her strengths, she was steadily declining internally and she struggled to manage the day-to-day expectations of her life. By the time she was a junior in high school, her emotional struggles grew to outweigh her strengths. She found herself in a desperate place, self-medicating with alcohol and drugs, and seeking friends with whom she could hide her growing despair.

This talented teenager's fears about revealing her pain and the response it might evoke from the adults in her life led her to wear a variety of elaborate masks. She knew what people wanted to see and hear, and she became a master at presenting each character in the various stages of her days – at school with her teachers, at home with her family, and in the community with her social group of peers. Teachers and other adults in her life who saw through the "performance" and expressed their concern touched her tender heart, yet became threats to the control she was determined to maintain. She would later tell a school assembly of students and those very same teachers that she strategically surrounded herself with people who would not challenge her, would not express concern, and who would enable her to maintain the act. She revealed that she sought and found people who would not hold her accountable and who would provide a haven for her to avoid addressing her struggles appropriately. Of course, this contributed to her worsening condition and over time she slid into darkness and pain, with no easy way out.

It's a challenge for parents to raise a child through the teenage years and to discern "normal" developmental behaviors and rebellions from the signs and symptoms of mental health concerns. My daughter hated being a teenager. She said it was painful for her and I watched her progressively work harder than other kids her age just to hold it together. In the winter of her junior year, she didn't have the strength to keep

working that hard and she decided to put an end to her unbearable pain. She attempted suicide. She was only 16 years old. It's important to note her age, not only because of the tragedy of seeing a girl with her whole life ahead of her driven to such desperation, but from a clinical standpoint, I was told that there were certain diagnoses that could not be formally made at that age. What I heard was that the doctors didn't really know what was wrong and this led me to wonder, how can I know what to do to help my child if I don't know what is wrong with her?

Digressing for a moment, I'd like to make a point on the topic of diagnosing and labeling. Just because someone cannot be fully "diagnosed" with the name of a medical disorder that fits exactly into a particular definition that can then be billed to insurance to compensate for treatments should not mean that we are unable to identify a child's lagging skills that outweigh

when she turns 18, we can label her and then decide what to do regarding that label.

I was a mom who was unwilling to accept that destiny (and that risk) for my child. I didn't buy the medical business model that seeks a billable code in order to determine adequate clinical responses to a child in need. After all, she was only sixteen years old. I knew that we had two more years where I could "call the shots" as her legal guardian and another half dozen years of brain development remaining. I was determined to do everything possible to counter the raging and debilitating dysfunction that was ravaging my daughter's life before it set in permanently.

I sought open-minded and ethical professionals to give me information and their opinions. I scoured the internet for information about adolescent behavioral health and treatment approaches. I networked with advocates, who helped me to learn what to say to

hospital staff, administrators, and insurance managers to remind them that they were in part responsible for my daughter's safety, even after she was discharged from their care. I researched comprehensive treatment planning and medical case management. Because I was determined to do everything possible to afford my child the opportunity to survive whatever was plaguing her, I

stepped into the role of coordinating all of her care. I learned about treatment options and a variety of providers. I learned how the current system works so that I could get it to work for my child. And these advocacy skills paid off.

Through my refusal to accept a second inadequate discharge plan from a children's hospital setting, I pushed the inpatient therapists to look more closely at the options available to my daughter and which would meet her clinical needs. My daughter was transferred to a residential setting, where her case manager accepted me as part of the team. And we all worked together to help this girl with the rest of her life ahead of her to find a path to healing.

In this particular residential setting, the focus did not seem to aim for a single "diagnosis" or label. The therapists organized around dual diagnosis and co-occurring disorders, and the intensity of the treatment day matched the intensity of my daughter's resistance. Her case manager saw her potential to heal and also knew

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their strengths at any given stage of their development. We can identify what is in the way of a child demonstrating the functional abilities to meet expectations placed on them. We can target skill deficits and teach these skills. Because of my experiences, this is how I think we should define "treatment." I would like to see this as a way to help parents organize their ideas about what is "wrong" with their children who are struggling with a learning disorder, mental health condition, developmental delay, or all of the above.

Two weeks following her discharge from an adolescent psychiatric unit (which is essentially mental health intensive care), my daughter had another emotional breakdown and attempted suicide again. When she was admitted to the same psychiatric facility, the psychiatrist assigned to her told me, "your daughter is likely to have recurring hospitalizations before she gets the help she needs and when she turns 18, she'll likely be diagnosed with borderline personality disorder." I heard, there is nothing we can do for her now because of her age and

that it was critical to involve me as an essential participant in the process. At the end of the day, or the week or the month, the young clients receiving services in treatment facilities will likely return to the context of their homes and families, however that family is configured. Until our kids are fully developed adults, approaching mid-twenties in many cases, it is the context of family within which they will likely continue their treatment plans. In the case of my daughter, this was the “secret sauce” that led to our successes. At discharge, we had a comprehensive treatment plan that involved: ongoing individual therapy for each of us, family therapy, individualized education plan (IEP) at school, peer support groups, a newly adopted treatment dog, well-defined structure and family behavior agreements, clearly articulated expectations and accountabilities, and no questions about the priority of addressing mental health needs above all else.

In my own therapy sessions, I learned what belief systems and life views kept me locked into certain dynamics in my relationships with my children. I learned how to parent my daughter for who she is and what she needs, rather than comparing her to another child in the home or what I needed when I was her age. I learned how to manage my own emotional triggers and to hold the position of adult in the home, accountable

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for holding age-appropriate expectations and enforcing balanced rules and safety plans. I learned how to hold tenderly my compassion for her struggles, while simultaneously supporting her to grow stronger and overcome them.

Over time, we have all settled into our new ways of being in the world and my daughter, quickly approaching her twenties, has the confidence that supports her to create a life that is joyful and fulfilling, as well as the skills to push through life’s obstacles and challenges with grace.

In a letter to me, my beautiful daughter shared her perspective reflecting back on that part of our journey together. I share it with you in the hopes that you will find the courage and the path to healing in your own family:

“Everything that’s happened needed to happen... I needed to fight you all these years so that I could prove how strong I was. I needed to prove how strong I was so that I could use my strength to keep me going. I needed to be challenged and put in my place so that I knew I wasn’t the only person I was hurting. I needed to fall in order to get back up. I needed to fall so that you could help me up. I needed you. I needed you to force me to see that I needed me more than anyone else. I needed you to push me. I needed you to make me do what scared me the most; to do what I needed to do. There is no other person in the world that would have done that for me, and you knew that better than I could at the time. Today I know this. And I never would have known it if we hadn’t gone through everything we have.”

AUTHOR

E. M. Lofgren is now a full time family educator and advocate, serving families of children with behavioral and developmental challenges. She is developing a web-based tool kit and educational workshops for parents to learn how they can advocate for their children and effectively navigate children’s mental health systems. If you would like to learn more, you can reach her at CareConnectorSolutions@gmail.com.

