

Navigating Sleepless Nights: A Mother's Guide to Special Needs Planning

By: [Amy Boulware](#)

I was driving to work on August 24, listening to Lady Gaga on my Pandora radio station, when suddenly, I had a strong urge to call my younger daughter, Hannah. We talk regularly, so it isn't unusual that I call her on my way to work, but this day was different. I just had to connect with her. We chatted, and she told me about her plans for the week ahead and the kids she is mentoring as an academic counselor at her university. We said we loved each other and were off to our day's activities. About two hours later, she called me back and said, "I know why you had the urge to talk to me. Do you know what today is?" She reminded me that 11 years ago, our lives changed forever. August 24, 2012, was the day that Hannah fell down a concrete flight of stairs in front of her high school after having an unexplained seizure. She suffered a significant traumatic brain injury that left her in a coma for weeks. When she woke, she did not know her name, how to walk, how to process information, or even how to eat.

Hannah and our family were facing a whole new world — one where she was now a child with a disability, and a hidden disability at that. We often talk about the "old Hannah" and "Hannah 2.0." Neither of us could believe that 11 years after her injury, we could start our day and not have that traumatic event be the first thing on our minds. Hannah has had a tremendous recovery with the help of some spectacular rehabilitation and therapy, but we all know that she is still someone who identifies as a person with a disability. This changed our family dynamic in so many ways. One thing I know for sure is that from the moment a child is either born with a disability or acquires one, like Hannah, parents worry. There are many worries that go through the mind. Will my child be able to be independent? Will they have the support they need? Will they ever live without care? Will there be enough money to pay for the care they need? Can they make decisions for themselves? Are there ways to prepare for the future? These sorts of questions are endless, and they keep parents and family members awake at night. I have them, I know. The fear can be paralyzing. Many families don't know what to do or who to turn to.

I felt compelled to write about this because of a family I am working with right now. They gave me permission to tell their story in hopes that it would help other families realize that ignoring these fears and not planning ahead is not the answer. This individual with special needs was born with developmental disabilities. He grew up in a small town where his parents cared for him, he went to special schools, and lived a quiet life in his family home. When both of his parents passed away, the family plan was always for him to go live with his sister and brother-in-law. They picked up where his parents left off. He lived with them, they cared for all his needs, and they aged together. This is a family that knew from his birth he would need care, and his sibling had agreed to be the person who would do that when their parents passed away. There were no formal agreements, conservatorship, or real understanding of the benefits he might be eligible for. It was just a family obligation that was passed on.

His sister's adult son, who happened to be an only child, begged his parents to do some special needs planning for his uncle. He knew he would eventually be the one to care for him but had no legal rights to do anything. Who else would there be? In many families, there isn't anyone. The nephew's parents did a portion of the planning prior to their deaths but didn't complete it. His parents passed away within months of each other, and now, the son has been trying to navigate the many disability systems, including Social Security, TennCare, group homes, and conservatorship, in a crisis moment. For his uncle to be eligible for certain benefits that would help pay for a group home, we (as his

attorneys) had to be able to prove that he had a disability prior to the age of 22. Where do you think we could find that proof? Can the nephew make legal decisions for him? Can we find care for him? Does he get Social Security benefits? Who is his payee? While grieving for his parents, the nephew has had to find the help to figure all of this out. I can assure you that a crisis is the worst time to do this work. However, can it be done? The answer is yes.

Our Chambliss special needs team is prepared to help families at any stage of their journey, but the best time to do this planning is before a crisis occurs. If worrying about a family member with a disability is keeping you up at night, we can help. We understand this from a personal and professional level.

Don't wait — contact a member of our [special needs planning](#) team today for assistance with any of the following:

- Special Needs Trust Planning
- Navigating Public Benefits
- Conservatorships and Guardianships
- Care Coordination
- Power of Attorney
- Able Accounts