

The Handbook for the Recently Diagnosed with Autism: (Spoiler Alert: There is None)

There's a scene in the movie *Beetlejuice* where Adam and Barbara Maitland (played by Alec Baldwin and Geena Davis), who have died in a car accident, find themselves in limbo (literally) and discover a guide called "The Handbook for the Recently Deceased." Barbara says, "Are we halfway to heaven or halfway to hell? And...how long is this going to last?" I can relate.

I doubt that the dead receive an instruction manual for the afterlife, if only because new parents don't receive a how-to guide for their babies while they're bumbling over car seats in the hospital parking lot and trying to figure out how to keep this tiny human being alive. You kind of learn as you go, seeking advice from people and sources you trust. When I walked out of Nemours Developmental Pediatrics, holding the small hand of my newly-autism-diagnosed son, I felt the same way I did as I carried him out of the Birthplace at Franklin Square: overwhelmed, confused, and in need of guidance.

The difference in this case is that as the newly-minted parent of a child with special needs, my level of responsibility has increased. Unlike the first time I brought Frank home from the hospital, I'm beginning to understand that Frank will require more intensive care than his brothers and sister. But what would be required of me in my new role? The first step for me is to figure out what he needs and how to get it to him. A simple handbook with step-by-step directions would be great, but there isn't one, so I'm making my own. Here's what I've done so far:

1. **Told friends and family members about the diagnosis.** Being a teacher I have found a ton of help from students' parents and fellow educators. I've also received a lot of apologies, which are not warranted. I'm honored that God chose me to be Frank's mom.
2. **Sent a copy of his diagnosis to school and follow up with his teachers.** His special educator is so insightful that she bought Frank a pair of red

noise-cancelling headphones to help him cope with excessive noise-levels, especially in gym and music.

3. **Registered Frank for the Maryland Autism Waiver** (at the immediate urging of many friends). I did it without knowing what it meant, but later discovered that it would offer him supports like respite care and housing if he needs them as an adult. I have chosen not to dwell upon the idea that he may never live on his own. Instead, I worry about what 5-year-old Frank needs. But, with a 10 year waiting list for services, I put him on the Waiver list right away.
4. **Contact our pediatrician.** The office told me that they'd make a note, but that he wouldn't need to see them unless he needed medication as that everything should be handled in school.
5. **Contact our health insurance provider.** They are setting us up with a case manager to help provide us with the behavior therapy resources we need.
6. I am reading an incredible book called "Uniquely Human: A Different Way of Seeing Autism" by Dr. Barry M. Prizant. Within 2 chapters, I understood why the book had a near-perfect rating on Amazon. I feel like the way I did the first time glasses were put on my face. I've been looking at my son out of focus for five years, and now I'm beginning to understand the "how" and the "why" of Frank, rather than staring at the "who" and the "what" I see before my eyes. I'm recognizing that many of his "problem behaviors" may actually be his means of handling excessive stimulus or expressing frustration in being unable to communicate what he's thinking or feeling.

I think I'm off to a good start despite the uncertainty that overcomes me at times. When I look at those bright blue eyes, hear that infectious laugh, and "wow!" over one of his incredible drawings, I know that taking his lead is the real secret to raising a child with autism. Please pray for us as we embark upon our journey. After all, there is no handbook.