



# I'd never be able to fix Meredith.

## Do I really need to keep trying?

By Sarah Barnes, TxP2P Volunteer

The irrevocability of it was what bothered me the most. I'd never be able to fix Meredith. She was as stuck with this unfortunate diagnosis as much as I was.

I spent my first year searching for answers and schlepping Meredith to therapy appointments, doctor's appointments and play groups with typical babies and mothers that had no idea what to say to me. Meredith was my first baby as well, so I was doubly clueless.

One time I was at the grocery store with Meredith long before she could walk and an older woman noticed I was carrying her. "You are spoiling her," she said. "She can walk."

"She *can't* walk," I told her. And of course my thought bubble said: Did you really just give me unsolicited advice on one of the hardest goals of my daughter's life while deciding between the Honeycrisp and Golden Delicious?

What a weird planet we live on, parents like us.

Comments like that really ruined my day, but I had plenty of positive karma from support groups and the therapists from Early Childhood Intervention, the statewide program to help families get therapy and other services for their child with disabilities. I've been lucky that the vast majority of teachers and therapists in Meredith's life have been caring, helpful and driven.

Meredith has an unusual diagnosis called Agenesis of the Corpus Callosum meaning the fibers of her brain creating a bridge between the two hemispheres did not form and she has a small cerebellum also due to a Dandy Walker variant. I found a few people to talk to early on who had the same diagnosis for their child, but it's really hard to see into the future until you've walked it.

Everyone warned me about middle school, however, and, man, were they right. It has been an epic struggle to find the social support let alone the best curriculum for Meredith in middle school. I'm not sure where the disconnect was between Meredith's hugely inclusive experience in elementary school and her sudden relocation to an island with few friends and very little exploration off the island unless it was the entire group of Life Skills castaways. She seemed to lose her rights and her social status as an individual.

I guess I turned into the mother from hell when I began writing about all that in the Austin American-Statesman, but I felt the need to open it up. I suppose the biggest lesson I learned is Meredith's education is only as good as the scheduling, which is deeply dependent on how many aides are in the classroom.

I recently help start a vegetable garden to be shared by kids in regular education and Meredith's classroom. It has been successful and is providing an option to laundering team uniforms and don't get me started on that. Though

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I still make strong recommendations almost every week for what I'd like to see in the classroom, there are other areas my heart is now seeing differently.

Meredith has irretrievable quirks and physical limitations. She will never walk typically or write her name by herself or understand social skills, but she will say "bon appetite" when she feeds the cat. Do I really need to keep trying to change her, to make her walk better, see better?

Her physical therapist recently let her go because she said Meredith had hit a plateau. I'm learning to appreciate Meredith for what she has become. It's far more compassionate than hauling her in for another therapy appointment. I love her for the unique teenager she is. Sometimes when I'm annoyed with her behavior, I just think about being in her shoes. I imagine myself with a leg being two inches higher, one eye being shut down, not being able to answer a question when asked and extreme inexplicable anxiety over getting in the car to go somewhere.

That's one tough road and Meredith rides it every single day. All I can really do is help her pick the right lane.

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