

Recalculating

By: Nici Wooding

I absolutely hate to admit this because it's such a stereotype, but I am not good with directions. Never have been, probably never will be. Anyone who knows me knows it's true. I rely on my GPS more than I should, I get turned around at the drop of a hat, and I will stick to a route I know even if it takes me longer, simply because I don't want to go the other way. I want to stick to what I know. And of course, when my planned route is ruined by a closed road or a construction area, the feeling of dread when I hear the GPS say "recalculating" is hard to describe unless you're like me and want more than anything NOT to be lost. (And yes, it's happened a few times, and NO it did not go well.)

When Leah was born, her diagnosis of Down syndrome was unexpected. We had our suspicions and strong feelings that it was a possibility, but it was still unexpected nonetheless. In that moment, the feeling in my stomach was not much unlike those moments on the road. I took a wrong turn and now the GPS was saying those dreaded words again...."recalculating...."

My fear kicked in and all I could think about was how to get back onto the road I knew. The one I was expecting to drive on without any complications. The one I was going to take all the way to the end and watch the sun set into a beautiful orange-purple sky.

But we weren't on the road we expected and we panicked. We started thinking about how things were going to be so different and how we weren't prepared and how we just didn't know what to do.

But we figured it out. Little by little, we figured it out. We found our tribe. We got the resources. We found our people. We got the therapists and we got the compression vests, and we got the orthotics for her shoes, and we went to all of the appointments and we read and read and read. And we learned as much as we could about Down syndrome. We followed all the right people on Instagram. We listened to all the right podcasts. We tried to do all the things. And we were doing okay, and we felt like we might finally be getting our footing. And then we started noticing some things.

It was small at first—probably nothing, really. Right? It's nothing. I didn't just see that, did I? These were the questions that were constantly filling my brain when I would notice something about Leah that seemed eerily familiar. An aversion to crowds and noise, an inwardness and difficulty with new people and settings. Sensory seeking behaviors like spinning and watching flashing lights. Self-stimulatory behaviors like flapping her hands near her face and moving her eyes in exaggerated positions. I saw these things. I thought about them. And I kept them to myself. For a long time. Until I couldn't anymore and we had her evaluated, and she was given a dual diagnosis of Down syndrome and Autism.



And in that moment, the same feeling was in my gut. That terrible sinking feeling. I could hear the dreaded words just as I was beginning to feel grounded. “Recalculating....” AGAIN. And now the map is useless. And now I can’t figure out where to go—even though I’ve been here before. Nothing makes sense and all I’m left with is that awful feeling in my stomach and an exhaustion that is hard to put into words. It’s an exhaustion that comes from something that isn’t talked about very much—especially within the Down syndrome community. And it needs to be talked about more.

I’m exhausted from feeling the pressure to have my daughter fit a mold that wasn’t made for her. I’m exhausted from trying to bend and twist things just so she can be accepted by those around her. And please hear me—Leah is loved. She is loved beyond measure by so many amazing friends and family members unconditionally. BUT— she is living in a world that celebrates what a person can DO. What a person ACCOMPLISHES in their lifetime. NOT who a person IS, exactly as they are. Full stop.

When Leah was born, the pediatrician reassured me by telling me that people with Down syndrome are going to college, living independently, starting their own businesses, etc, etc, etc. And at that time, it brought me great comfort to hear that. But now, even just three and a half years on this journey and I know now that that reassurance was coming from a place of ableism. I was comforted by being told that my daughter had Down syndrome, BUT LOOK—she would be able to DO so many things! Look at these other people with Down syndrome! They’re modeling, starting their own businesses, and completing Ironman competitions!

And PLEASE hear me again—these accomplishments ARE amazing! And they should be celebrated. BUT—we have to check ourselves. Because when we talk about these accomplishments, and we send that next viral video out, and we rave about representation in the media (HELLO Target ads!) we keep perpetuating the expectation that THAT super accomplished person with Down syndrome is the one that is worthy of being talked about. THAT is the mold that people with Down syndrome (and any other type of disability) should fit into. THEN they are good to go. THEN they can be tolerated. THEN they can be shared, liked, and retweeted. THEN they can belong in the ableist society that only sees what they do and uses THAT as a measuring stick for worthiness.

THIS is why I’m exhausted. Because now my daughter has another thing that separates her even from her own peers with Down syndrome. She doesn’t even fit the mold for THAT. (And let me assure you that there IS an expected mold for Down syndrome. It’s hard to even write those words, but it’s true. The mold includes traits like being sociable, loving being around other people, being in a constant and never-ending state of happiness, and being sassy or the center of attention.) So what happens when your child doesn’t fit that mold? What happens when no matter how hard you try, it just isn’t working?

You love them.

You love them so much it hurts.

And then you throw away the mold.

Everyone in the Down syndrome community is always talking about being in “Holland” and I’m over here feeling like I’m on Mars. Or maybe Jupiter—it’s colder there, right? And it’s just not fair. Because I want the world for her. I would change the world for her. I would do absolutely anything for her. And I love her so fiercely it hurts, but this roadmap keeps changing.. and I just wish we could find our way home.