Ableism

An Essay by Heather House

Ableism: Discrimination in favor of able-bodied people

Did you know that ableism is kind of a problem WITHIN the Down syndrome community? Meaning, even though we are all in the same Ds boat, we are still comparing our kiddos' "accomplishments" and holding up those who are doing amazing things (like running marathons or getting married) as shining examples of how it will all be just fine, when there are other people with Ds who simply won't get there.

It's tricky. The reason I was devastated when we received Fern's diagnosis was because had all kinds preconceptions about having a child with a disability. I was thinking of all the things I assumed she could never do. So naturally I sought out examples of kids with Ds who were "thriving," by which I meant the child with Ds who was most closely achieving the things a typical child would. And social media was awash with cute pics of kiddos with Ds "achieving" milestones. From taking their first steps to learning to potty train to attending a typical kindergarten....all of it gave me hope.

But these celebrations also reinforce our beliefs that a person's worth is tied to what they can or cannot do.

I don't have a lot more to say about this. As someone who makes a list every morning and then decides at the end of the day whether it's been a good and "productive" day based on how many things I've crossed off that list, this thread runs deep within me. And our society. I have a lot to learn. And unlearn.



Here's a pic from our trip out west, taken on Fern and Sylvan's ninth birthday. How 'bout it!! They turned 9 while we were in Bryce Canyon and we celebrated with breakfast at the lodge, a modest hike in the morning, a horseback ride in the afternoon and a dinner picnic at Mossy Cave where there was a waterfall and stream running through gorgeous red rock. I am proud that Fern was able to ride a horse by herself (god bless Tabasco, the calmest, nicest horse ever). At the same time, it was super clear early on in our trip that we were either going to do everything I had on our agenda OR we

were going to have fun. It was frustrating to me when I first realized just how much I needed to modify my expectations, but we (wisely, I believe) chose fun. This often meant turning around halfway through our hikes or stopping for snacks fifty gazillion times and not always making it to the summit. Sometimes we skipped things altogether.

No one shows up more enthusiastically for a hike than Fern. She just told someone yesterday that one of her favorite things to do is hike. But if you've ever been for a hike with Fern, you know she's also the first to tire out and start complaining. Is Fern any less worthy just because her little legs give out before her twin's? Is she any more worthy because she was able to ride a horse by herself? ■



Editor's Note: The author shared this essay with friends and family in October, encouraging them to contribute to her daughter's Buddy Walk Team, "Fiddlehead's Fans"