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The Magnificence of Disability

by Susan Agrawal

Lately I've been reading the book *The Boy in the Moon: A Father's Search for His Disabled Son*, by Ian Brown. It's a memoir that many of us will identify with, a father searching to determine the meaning and value of his son's life, despite a rare complex medical condition and associated disability.

Near the end of the book, the author interviews Dr. Bruce Blumberg, a geneticist who also happens to be blind in one eye. He states,

We're arrogant enough to believe that sentience is all that counts. It's not all that counts. A sequoia is not a sentient being. But they count. There is nothing more magnificent. It doesn't require me to think about it to be in awe of it...But it's just a mistake to think of [children with disabilities] as *lesser than*. There's no lesser than. There's just different from. It isn't just great minds that matter. It's great spirits too.

The sequoia--the giant redwood of the west--is one of the most magnificent trees to grace our planet, and a wonder to behold. But does the sequoia talk? Does it walk? Does it read at a first grade level? No. Frankly, next to the average tree, one could even posit that the great sequoia is a tree with a disability, for it surely has a form of gigantism! All it does is grow, year after year for thousands of years, until it becomes a massive giant, amazing in its magnificence.

But it's not "lesser than," just different in its magnificence, and most would even consider it to be "greater than." Sequoias often invoke a spiritual response in people when they see them in person for the first time. Activists have been so inspired by sequoias that they have been willing to fight to the death to save them.

This got me to thinking about how we, even as parents, envision children with disabilities as "lesser than" much of the time, because we expect them to measure up to the average child. I learned early on that acceptance of disability has everything to do with expectations. We do not expect a sequoia to walk or talk or read. We can love sequoias, be inspired by them, and see their magnificence simply because we only expect them to grow and look beautiful.

Similarly, while a stunning angelfish has a brain and can move around, we don't expect it to walk or talk or make dramatic proclamations about its ocean environment. It's a fish,

after all, and it doesn't even have legs or lungs! Even our pet dogs, who rarely possess intelligence greater than that of the average two-year-old child, are not expected to master skills such as reading or talking. We love them anyway, praise them for their brilliance, depend on them, and care for them with great diligence. This is because we expect them to be dogs, and not something other than what they are.

The same applies to our children with disabilities and special needs. We unfortunately have the expectation that every child should walk, talk, read, behave, and socialize appropriately. But these traits are really not what makes us human, nor are they even that important in the grand scheme of things.

If we can eliminate our expectations, perhaps we can see the true value and meaning of members of our society with disabilities. Perhaps we can look at them like the great sequoias, magnificent in their splendor simply through the act of being. Our children with disabilities are truly as magnificent as the sequoia, if we can just look at them as they are, without expecting them to be something they aren't.

We need to step back and truly look at our children without expectations. We may just find that they are like the sequoias, teeming with splendor, filled with spirit, and most of all, magnificent.