

Already 19: Further Reflections on Parenting, Aniridia, and Being a Doctor

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The author, a family physician, reflects on raising a daughter with a rare eye disease, aniridia, and learning and memory disabilities as the daughter heads off to college. (J Am Board Fam Med 2018;31:303–304.)

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My daughter and I are cleaning her bedroom together as she prepares to travel across the country to start college. A born pack rat, my daughter seems to hold onto everything, from old amusement park wristbands to childhood games missing essential pieces to clothing that she hasn't worn since middle school. Previous routs of her room led to very little making its way into the "donate" or "discard" boxes. This time, however, is different. Already we have taken 5 packing boxes to Goodwill, and she barely lost her temper when I finally came clean that the large number of stuffed animals that went to the basement for "storage" over the last few years got donated to the church rummage sale this year.

Ten years ago, I wrote about my daughter, adopted from Korea and born with aniridia (a rare genetic eye disease with decreased retinal cells and no irises), being diagnosed with learning and memory disabilities.¹ There were many times during the last decade when I wondered what the future would hold for her. Now, a few weeks away from her first days as a college student, I think back on those years, and realize, as folk wisdom states, a village raised this "special-needs" child into an independent young woman.

It begins, of course, with parents...

- No one could ever accuse me of being a "helicopter mom" (my kids will tell you my advice for most of their complaints boils down to "deal with it"). But I realized that my daughter was going to need support and help. As we began the process of making specialist appointments and working through the red tape of the public school system, I realized how lucky my husband and I were: being well educated and financially well off, we had self confidence and social standing to successfully advocate for our daughter in a way we saw was lacking in the families of some of my daughter's peers.
- We could give our daughter chances to try lots of clubs and sports until she found a social niche in a youth circus. I could never get the knack of juggling even 2 balls, but she could juggle multiple balls while riding a unicycle. Watching her walk across a high wire or vault over a German wheel, knowing that much of the world around her was a blur, was a testament to her growing abilities to trust her physical body.
- We also gave her hours of our own lives. For years, I would sit with her while she slogged through reading and writing assignments. I read aloud to her from textbooks well into high school, as her vision and learning disabilities made that task painstakingly slow. Together, she learned (and I relearned) everything from American history to algebra.

And the influence of schools is profound...

- We learned a lot about what educators know helps children succeed—larger print, electronic tools, extra time for tests and assignments,

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chunking of instructions. The role of school support for special needs is immense, and something I had never learned as a physician. I now pass on this learned wisdom to my patients, especially given that the poor and disenfranchised often do not know what schools can provide.

- My daughter’s teachers always assumed that she would graduate and go onto college, and therefore, my daughter, too, never doubted that outcome. Throughout 12 years of public education, my daughter was encouraged to become her own self advocate, learning to share her disabilities and needs. When she got a part-time job at a local ice cream franchise, she was able to ask for, and receive, posted instructions at eye level for mixing the ice cream treats.

But an inner drive to do well is the essential pillar.

- A drive to do well is different, I think, from a drive to succeed. My daughter has not always succeeded. She really wanted a driver’s license, and managed to squeak by visually with a day-light-limited learner’s permit. However, she soon realized that the glare was too much, the signs still blurry, and she really could not judge how far away those cars were. Instead, family and friends stepped up to give her rides and she learned how to use Uber and Lyft, and when she moves to a city with good public transportation, she’ll figure out buses and light rail.

My daughter is going to a funky, small liberal arts college on the West Coast. She likes how it felt like family. My husband and I plan to retire to the West Coast eventually, but in the meantime, my daughter

will be at school 2000 miles away. As we packed away some of her childhood memories, she asked me how she was going to get home for winter break. Since we had already booked her plane ticket, and she was an experienced flyer, I was initially confused. Then she explained, “How do I get from one gate to another by myself? I can’t read the gate numbers and I get lost easily.” She manages her life so independently, that it never occurred to me that she cannot see well enough, especially in crowded, chaotic airports, to get from one gate to another. Luckily, we found the “needs visual assistance” link on the airline web site.

We went grocery shopping last week. As we got out of the car, she put her arm through mine as we walked across the parking lot. I thought nothing of it, as she has been doing something like that as long as I remember. It was bright and sunny, and she was essentially walking with her eyes closed to decrease the painful glare.

Ten years ago, I compared my daughter to a mighty lioness. Today, she is a young woman taking her first steps into independence. However, like that lioness who hunts with the pride, my daughter will always take with her, and will find in the future, her own pride of family, friends, teachers, coworkers, and advocates to support her. With them, she will continue to be that mighty lioness, roaring her authority across the savannah.

To see this article online, please go to: <http://jabfm.org/content/31/2/303.full>.

Reference

1. Elder NC. Almost 9: A personal essay on parenting, aniridia, and being a doctor. *J Am Board Fam Med* 2007;20:606–7.