A Future We Must Dare to Imagine

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I grew up alongside my intellectually and physically disabled brother, Michael. In some ways, he was like any other family member. We traveled as a family to Hawaii on vacations, went to restaurants for special occasions, and wandered around nearby shopping malls over weekends. People would often gawk at Michael when he made sounds or stumbled with his walking. My reflexive response as his protective younger sister was to stare right back at them intensely, which proved quite effective in lessening the unwanted attention. These early experiences forged a sort of ride-or-die relationship, and my brother and I found ourselves inextricably committed to ride out life’s challenges together, whatever the outcome and wherever that journey might take us.

Michael had epilepsy, and his seizures sparked a curiosity in me while learning about neurons in high school. I pursued research opportunities in neuroscience and charted a path to college. However, it was Michael’s multiple barriers to accessing the health care system that motivated me to become a physician. I wanted to be fluent in the medical language that physicians spoke so I could help my brother and people like him. I saw that as my purpose. The road to medical school seemed elusive, but I had a brother who taught me perseverance. How could I complain when he faced obstacles on a daily basis?

From a young age, I saw Michael have seizures. I learned how to recognize them, what to do and not to do, and the names of all of his many medications. I could recite them from memory. In fact, I did during many appointments, except for one. That day, Michael’s neurologist was questioning my family about his seizures, and I lost my train of thought. My brother’s medical appointments were high-stakes encounters. When Michael became an adult, he received Medicaid, and it was difficult to find a physician willing to accept the state-funded insurance. In addition, because of his intellectual disability, Michael stood out, and clinical offices were not welcoming places. One morning, after more than an hour of waiting, a receptionist asked us to relocate to the children’s area because Michael, nearly 30 years old at the time, was making too much noise. We complied with the request, completed the visit, and started working on obtaining another physician.

During appointments, most physicians did not make eye contact or speak with Michael. Instead, they directed their conversations to family members without asking about his communication abilities. While it was true that Michael could not easily articulate many wants or needs, he understood a lot. No matter how much we said or did on his behalf, it was not the same as allowing him to say it for himself in his own way. We did not feel empowered to tell a physician what to do or how to act, given the limited options we had to choose from.

We eventually found physicians who made the effort to connect with my brother, see him when needed, and care about him as a person. That did not come easily, however, and it still saddens me that we had to endeavor so greatly and spend so much time locating them.

Because I am now a physician myself, having a positive influence on the lives of others is important to me, including those with disabilities and their families. I am grateful that I get to share that perspective with medical students and resident physicians in a new medical school at the same university where I once was a college student. I am also proud to care for patients who are medically complex and socioeconomically fragile in a safety-net hospital that delivers the highest level of care in the community to everyone, regardless of their ability to pay. Growing up with my disabled brother, Michael, undoubtedly shaped the person I am today and the career decisions I’ve made. He showed me a future I would not have dared to imagine.

While clinics have become more accommodating and patients now experience greater autonomy in their discussions with physicians than ever before, people like Michael remain at a considerable disadvantage. Compared with their peers without disabilities, individuals with intellectual disabilities still lag behind in mean life expectancy.1 In addition, people with all forms of disability experience worse health outcomes and greater difficulty using health care than the rest of the population. Despite being at higher risk for chronic health conditions, such as diabetes, hypertension, and heart disease, they receive fewer cholesterol screenings, blood pressure checks, and other forms of preventive health care.2,3 These disparities in health, differences in health outcomes based solely on being a member of a socially disadvantaged group, are injustices.

I believe in a better future. Adults with intellectual disabilities are living longer. Supporting them later in life requires communities that can keep pace with their unique service needs now.4 People with disabilities do not only meet impediments in the delivery of health care, though. Assistance with reliable transportation, employment, and housing is equally important. These social determinants of health can mean the difference between a life of self-determination and one of complete dependence on others.

When I moved to another city to start medical school nearly 2 decades ago, my brother came, too, along with my parents. Leaving him behind was just not an option, and our family functioned most effectively together, in one place. We relocated again for my family medicine residency, back home to Las Vegas, Nevada, where I remain today. My family leveraged the best support network possible around my brother to allow him to enjoy as independent a life as he could, given his severe intellectual disabilities. That is not to say there were not missteps along the way, necessitating fierce advocacy by our mother, who also served as my brother’s legal...
guardian. She stood up for Michael when his rights as a person with disabilities had been violated, and we rallied to fight for that cause at every turn.

My brother died recently following a brief illness, which has left me wondering, "Who’s going to sneak a bite of my grilled cheese sandwich now or gulp down an entire glass of chocolate milk whenever the opportunity arises?" There was only 1 person I knew who could reliably carry out that role. Although he was only 49 years old, the true measure of my brother’s life has yet to be fully realized. As I envision a world without Michael, an existence I have never known before, I recognize that my brother is still right here with me. All of the joys of knowing him, the heartache of seeing him struggle, and the exhilaration of watching him ultimately thrive will never leave me. Rather, they will push me forward and continue to remind me of how much more there is to be done for the most vulnerable citizens. During this era of tremendous creativity and innovation everywhere around us, I have no doubt that we will devise new solutions and become a more inclusive society in the process. Now is the time for a future we must all dare to imagine.

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