

American Medical Association Journal of Ethics

April 2016, Volume 18, Number 4: 438-441

MEDICAL NARRATIVE

An Open Letter to Medical Students: Down Syndrome, Paradox, and Medicine

George Estreich

If you're reading this, you could be anyone—a bioethicist, a Facebook friend, an adult with Down syndrome—but the “you” I have in mind is a future clinician. As a writer and parent of someone with Down syndrome, my aim is to share questions and insights that may be useful to you. Clinical encounters involving people with intellectual disabilities can be both charged and complex; understanding the complexities may help improve the encounters, by helping clinicians [see the patient more clearly](#). I will focus on Down syndrome, because it's what I know best, but ultimately I wish to emphasize similarities between people with Down syndrome, people with other disabilities, and those of us who, because we lack named conditions, are presumed to be “normal.”

At this point, you may be expecting to be scolded or inspired. In the first case, I would recount an anecdote involving an insensitive physician and warn you against analogous behavior, perhaps cautioning you against language offensive to people with disabilities. In the second, I would offer an appealing, positive story about my daughter, thus inspiring you to recognize her essential humanity, to see her as a person and not as a diagnosis.

These are common scripts, and they have their uses. Still, I try to avoid them. Practically speaking, no one was ever scolded into enlightenment, and what we call “inspiration” is often weaponized sentiment, a battering ram with a Positive Message printed on the end. Although I've written a book [1] about my daughter, the humanity and value of people with Down syndrome—and of people with other disabilities, however defined—is a starting point for me, not a persuasive destination. One should not need an inspiring story to be valued.

I wrote the book about my daughter for many reasons, but one was that since the attention she drew was inevitable, I might as well work with it. If people were going to stare, I might as well lend some depth to the picture; because, as I found, they were often staring at a projection. This projection—call it a huggable ghost—was a vague shape, a diagnosis with a personality, a mix of sweetness and tragedy, of angels and heart defects and maternal age. It was a way of imagining Down syndrome, but it hid the individual. The projection, the ghost, obscured the child.

In that book, my project was to restore the child to view. In this letter, my project is to help banish the ghost from the exam room. To that end, I want to discuss some of the obstacles to seeing people with Down syndrome clearly and on their terms, and to suggest a paradox: since one of the greatest of those obstacles is the medical description of the condition, a thoughtful physician will need to both absorb that descriptive knowledge and be able to set it aside.

No one says that people with lung cancer have a particular personality, but the idea that there is a "Down syndrome personality" (sweet, affectionate, cheerful) is, in my experience, common among clinicians. It's less common among parents, but even when asserted, it's usually to support an individual story, and not an idea of diagnostic sameness. Parents are intensely aware of a child's distinct personality and situated life, her story in time.

The tendency to equate diagnosis with personality has roots in medical history, and ultimately in the history of Western thinking about race. The condition now known as Down syndrome was first described in Western medicine in 1866, by the young physician John Langdon Down, then medical superintendent of the Royal Earlswood Asylum for Idiots [2]. When Down christened the condition "Mongolian idiocy," believing the "idiots" in his care to have descended a hierarchy of races *in utero*, he grafted ideas of race onto ideas of disability. It was a brilliant error, a stroke of blurry insight: the list form could incorporate both observable features and presumed ethnic characteristics. Down was no simple racist, and in his treatment of asylum residents, he was ahead of his time [3]. But he saw the individuals under his care through the lens of group attributes.

For this reason, the claim that people with Down syndrome are "sweet," however well intentioned, makes me uneasy. It feeds the perception that Down syndrome is the "good" special need, the appealing one, which seems unfair to kids with behavioral difficulties. It can also misfire in any number of ways: children with Down syndrome who are expected to be sweet but aren't can be seen as disappointments; children with Down syndrome are often expected to give hugs to strangers, a real problem given the high rates of sexual abuse committed against women with intellectual disabilities [4]; children with Down syndrome can be seen mainly in terms of static behavioral qualities and not in terms of what they might learn.

But most of all, "sweet" is something you say of a child. People with Down syndrome now have a life expectancy of around 60 [5]. If we think of them as permanent children, we will be less able to imagine a place for them in the world as adults.

There are few certainties with Down syndrome. Because we know where it begins (with a nondisjunction, or a failure of a chromosome pair to separate during cell division) and what results (an infant with a suite of typical features), we can believe, too easily, that it

is known. But the condition is incredibly variable, and those variations, entering a changing world, result in many different outcomes.

Ironically, among all the [probabilities](#), [possibilities](#), and distant chances associated with Down syndrome, the primary certainty—what used to be called “retardation”—is not clearly within the domain of medicine. To have an atrioventricular canal defect, or leukemia, is one thing. But to be less able than most to manipulate information, to reason abstractly, is another. It’s not only that people with Down syndrome have a range of abilities, which overlaps with the range considered “normal.” It’s that ability itself cannot be measured or considered outside of social context.

Even setting aside the long history of underestimating what people with Down syndrome can do, it’s worth noting that people with intellectual disabilities, besides being among the most despised minorities in our culture, are cast in a harsh light by a society that prizes intellectual ability and accomplishment. Negotiating our text-heavy, Information Age democracy requires an unprecedented degree of literacy and technological ability. In work, in education, those abilities are heavily incentivized. Indeed, our educational system encourages us to equate intellectual performance with self-worth, to motivate ourselves by seeing ourselves as our grades and accomplishments. Teaching English at the university level, I’ve seen this in many of my students—and in myself, too, a lesson I’ve learned too deeply to forget.

Which brings me back to you, reader. You don’t get into medical school without taking ability itself—and particularly intellectual ability—seriously. The entire project assumes capabilities that tend to be diminished in people with Down syndrome: skill with language and numbers, ease with abstraction, the ability to process, retain, and manipulate large quantities of information.

A question, then, is how to imagine the value of people who don’t have those abilities: how to value your own achievement without devaluing those for whom those achievements are difficult or impossible. Much in our culture, from ubiquitous insults based on intelligence to the medical definitions of normalcy to the relative invisibility of people with disabilities, teaches us separation. Clinical encounters tend to take place across a gulf, a chasm both narrow and deep. The question is how to step across it.

The divide between doctor and intellectually disabled patient can be framed as a divide between able and disabled. But I think it is best seen in terms of interpretive power.

To be intellectually disabled is to have your life be synonymous with an opinion not worth listening to: on Facebook, in every comment section, in conversation, that’s what the words *idiot*, *moron*, and *retard* imply. Conversely, being a clinician confers authority: your words matter, weighted not only by study, experience, and your resulting expertise,

or by the prestige accorded the profession, but also by the white coat, the stethoscope, the successive human barriers (e.g., receptionist, nurse) that frame an appointment, the ritual of gates dividing you from the patient.

You have, in other words, power to declare meaning. Paradoxically enough, your best course may be to refrain from using it. That is, apart from treating a given patient with Down syndrome like any other, the power to declare meaning entails *not* pronouncing what a patient is or what her life means, but instead learning to listen.

From the moment a child is diagnosed with a disability, her parents are swamped with interpretations, advice, and predicted futures. But predictions and interpretations, even comforting ones, may be less useful than an honest uncertainty. For any child, the agents of nurture—parents, clinicians, therapists, educators—are there to help keep her future as open as possible. That way, the child, when she is ready (when she is no longer a patient, no longer a child) can begin to find her own way, and to choose the meanings for herself.

References

1. Estreich G. *The Shape of the Eye*. New York, NY: Tarcher Penguin; 2013.
2. Down JL. *Observations on an Ethnic Classification of Idiots*. 1866. *Clinical Lectures and Reports by the Medical and Surgical Staff of the London Hospital*;vol 3;259-262.
3. Ward OC. *John Langdon Down, 1828-1896: A Caring Pioneer*. London, UK: Royal Society of Medicine Press; 1998.
4. Wissink IB, van Vugt E, Moonen X, Stams GJ, Hendriks J. Sexual abuse involving children with an intellectual disability: a narrative review. *Res Dev Disabil*. 2015;36:20-35.
5. Bittles AH, Glasson EJ. Clinical, social, and ethical implications of changing life expectancy in Down syndrome. *Dev Med Child Neurol*. 2004;46(4):282-286.

George Estreich is the author of a memoir about raising a daughter with Down syndrome, *The Shape of the Eye* (Penguin, 2013), which won the 2012 Oregon Book Award in Creative Nonfiction. His prose has been published in *The Open Bar*, *Biopolitical Times*, *The Oregonian*, *Salon*, and the *New York Times*.

Related in the *AMA Journal of Ethics*

[The Curriculum of Caring: Fostering Compassionate, Person-Centered Health Care](#), April 2016
[Keeping the Backdoor to Eugenics Ajar?: Disability and the Future of Prenatal Screening](#), April 2016
[Prenatal Risk Assessment and Diagnosis of Down Syndrome: Strategies for Communicating Well with Patients](#), April 2016

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

**Copyright 2016 American Medical Association. All rights reserved.
ISSN 2376-6980**