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Normal Human Variation 2.0

A teenage boy on the autism spectrum who aged out of pediatric care was referred to the Progressive Evaluation and Referral Center (PERC) at UPMC Montefiore but kept missing appointments. When Kristen Ann Ehrenberger, the center's director, noticed the pattern, she called the young man's mother to find out why.

"When I got his mom on the phone, it turned out that she wasn't used to seeing him as needing attention for complex medical needs," Ehrenberger (Res '20) says. "She saw her son as a healthy teen who happened to have autism."

Ehrenberger, an MD, PhD assistant professor of medicine and pediatrics, believes the mother was also trying to shelter her son from stigma that people with physical and mental challenges face.

Having earned her PhD in the history of medicine with a focus on nutrition and public health, Ehrenberger looks closely at how people with disabilities have been stigmatized through time. For instance, when researching post-World War I nutrition in Germany, the historian discovered that some institutions, like mental asylums, were left out of the country's rationing program. The idea that it was OK to neglect the "impaired" was gaining momentum. Jurist Karl Binding and psychiatrist Alfred Hoche wrote arguments in favor of the "destruction of life unworthy of life"—meaning those who experienced mental or physical disabilities. (Eugenics had its proponents in the United States, as well.) Those ideas helped shape the century's tragic and monstrous history.

Ehrenberger's insight on such ideologies, and their modern remnants, informs how she practices medicine and works not only to advance care for those with complex medical needs but also to change the narrative thread.

"What's a common label for people who use wheelchairs?" she asks. "People who are 'confined to a wheelchair.'" But she argues, "You're confined to a house. You use a wheelchair to move around."

She prefers thinking of disability in a more social way. Bodies are diverse, she says. Some people communicate with words, others use signs. Some people walk on two feet while others use wheelchairs.

Ehrenberger wants to broaden this message to eliminate stigmas people with mental and physical challenges face. She says it's not just a matter of semantics—such as simply replacing "retarded" or "crippled" with "disabled" or "handicapped." Using different adjectives doesn't go far enough; she wants to alter perceptions.

At PERC, center staff—including Reed Van Deusen (MS and Fel '08), associate professor of medicine, and clinic founder Alda Maria Gonzaga (MD '00, Res '04, MS '06), associate dean for student affairs and professor of medicine and pediatrics—are trained in both pediatrics and adult medicine. Founded by Gonzaga in 2008, the clinic accepts those with complex medical needs ranging from autism spectrum disorder to cerebral palsy to rare genetic disorders. PERC serves more than 300 patients. Most transition to the clinic between 18 and 26 years old.

Ehrenberger has learned that while labels are harmful in most instances, there are situations in which they are useful. She points out that autistic people tend to prefer diagnosis-first language to person-first language—that is, saying "an autistic person" rather than "a person with autism." They are likely to say that neurodiversity is an integral part of who they are, and that they cannot be understood without it. However, people with other disabilities often prefer person-first language.

To Ehrenberger's chagrin, "The disability medical model is that there's something wrong with the mind or body," she says. "[People with disabilities] exist on a spectrum of normal human variation, not as a group that's easy to separate from 'normal' or 'healthy' patients."

—Michael Aubele

—Photo illustration by Elena Cerri