



Discovering Difference: A Narrative Medicine Investigation of Lived Retrospective Diagnosis

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Discovering difference: the experience of newly learning in adulthood that one has a longstanding cognitive or perceptual difference from the norm, particularly one that may be considered pathological. It can occur when the condition has remained undetected, such as becoming aware that one is color blind, and/or when the diagnostic categories themselves have shifted, as with the emergence of autism spectrum disorders or ADHD. I articulate and deploy an evolution of narrative medicine as a robust research methodology comprising interdisciplinarity, narrative attentiveness, and creating a writerly text. Beginning with my own experience of discovering difference, I explore the issues it raises— from communicability to narrative intelligibility to different ways of seeing. I map

the phenomenon's distinctive narrative arc through the stages of recognition, subversion, and renegotiation, and finally discuss this trajectory in light of others' experiences. Better understanding discovering difference will aid those directly affected; moreover, it serves as a bellwether for how we will all navigate advancing biomedical and genomic knowledge, and how we may integrate medico-scientific revelations with what we understand to be our identities.

Danielle Spencer is a faculty member of the Program in Narrative Medicine at Columbia University. She is a co-author of *The Principles and Practice of Narrative Medicine* (Oxford University Press, 2017) and her work appears in a range of outlets, from *Ploughshares* to *The Lancet*. Her research interests include the intersection between narrative, identity, and diagnosis; bioethics and speculative fiction, and healthcare professions pedagogy. Spencer worked as artist/musician David Byrne's Art Director for many years, collaborating on and exhibiting a range of projects, as well as with photographer Nan Goldin. She holds a B.A. from Yale University and an M.S. in Narrative Medicine from Columbia University, and a Ph.D. des. in American Studies at Johannes Gutenberg University Mainz.