

Faculty Spotlight: Maya Sabatello, Ph.D., LL.B.

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Interviewee: Maya Sabatello, Ph.D., LL.B.

Title and Department Affiliation: Associate Professor of Medical Sciences at the Center for Precision Medicine and Genomics, Department of Medicine, and Division of Ethics, Department of Medical Humanities and Ethics, at Columbia University, where she also co-directs the

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When my cousin first heard about the Kehlani custody scandal, I first wondered—when did the inner workings of our most sacred relations, the interpersonal ties between mother and daughter and those in a romantic partnership, become so easily gathered and disseminated via twitter? The ex of the R&B star apparently cited many reasons for attempting to take custody—including the fact that she “told [him] she had been diagnosed with a bipolar disorder.” He went as far as demanding a psychological evaluation of Kehlani, using her mental health as a basis to challenge her parental rights. This gave me pause.

It might be easy for some to dismiss this situation as worrying, since it involves a celebrity and thus the threat of this occurrence feels distant from the everyday person’s. However, I have seen single mothers in my own community taken to court with claimant reasons that cannot be professionally substantiated. So, the fact that even a rumor of a psychiatric illness could undermine a person’s perceived capability as a caregiver fills me with dread. This information is not necessarily misused but often mentally mishandled—harming the way one is viewed in our society. The news of this happening left me reeling, and I could not help but reflect on my own experience with custody proceedings at 13, remembering how my mother’s ability to care for me was questioned. Despite being well-educated, well-fed, and well-cared-for by my mom, our little family was seen as inherently flawed or in need of something simply because the “normal” was broken by my mother being a single parent. At what point does the word *different* become synonymous with *incapable*? What role do we individually play?

I. A Transdisciplinary Background for a Transdisciplinary Problem

“Legal background, disability advocacy, as well as the world of how people with psychiatric conditions are treated in society and the clinical setting have always raised a lot of interesting

questions for me.” It is her transdisciplinary, professional experience as a litigator of medical negligence cases, disability activist, co-drafter of the Convention on the Rights of Persons with Disabilities, and bioethicist within the realms of both medicine and law that led Dr. Maya Sabatello to pursue inquiry into the ways in which a presumed or official psychiatric diagnosis may bleed into other areas of an individual’s life—shaking courtroom decisions and family dynamics.

“We know that psychiatric conditions run in families,” with the genetic understanding of these conditions being mainly shuttled towards improvements in elements of clinical practice that include diagnostic tools, preventative efforts, and treatment options. With a K01 grant from NHGRI, Sabatello and her team explored the ways in which psychiatric genetic data might also impact legal decision-making and litigation, yielding the paper of interest— *Psychiatric genetic essentialism and stigma in child custody proceedings: public views*.

With a disability rights advocacy perspective, Sabatello notes that “stigma against people with disabilities—including those with psychiatric conditions— leaps outside of clinical settings,” and, with this project, she explored how genetic information feeds genetic essentialism that unjustly bolsters misconceptions and stigma at the detriment of these individuals who have little control over their illness formation.

II. Methodology: Psychiatric Genetic Essentialism and Stigma

“With behavioral and psychiatric conditions, we are rarely talking about anything that is monogenic.” We are not dealing with things such as paternity where we can say “there is a 99.99% likelihood of a parental match.” Instead, we are looking at conditions that are more

complex, involving many environments that interact with the many genes and with lifestyle choices. ”

This complexity required a thoughtful approach and methodology—leading Dr. Sabatello and her team to utilize vignettes to explore the meanings or biases of participant responses. “The beauty of vignettes is that it takes complex cases and simplifies them into a short story in which you can vary the key variables you want to explore.” You take the same case, change one or two variables of interest, and then ask different participants the same questions,” looking to see if this alters views. In this study, the primary question was “would the claimant parent—parent who claims they should have full custody instead of sharing custody with the other parent (who is claimed to have a psychiatric condition)—be granted custody?”

The findings express that, although the genetic information did not have a direct impact on custody decisions, “91% of participants would have awarded custody to the claimant parent.” Additionally, the team conducted a newly created Implicit Association Test (IAT), finding that participants held “a strong association between psychiatric conditions and bad parenting” and “presumed (the parent with psychiatric condition) as less capable of daily life activities.” Per Dr. Sabatello, this highlighted the necessity for a discussion on bias and risk for "civil death," which has been raised in the disability rights discourse.

III. Civil Death

There has been an effort for a long time to reclaim mental health conditions as a disease like any other— for example, “if one has a genetic condition that makes it such that one needs to use a wheelchair, most are not blaming the person for needing to use a wheelchair.” This is not often a view granted to those with mental health conditions, but Dr. Sabatello shares there was hope

changes would be made. That, with genetic information, “we were going to take away the blame.” However, “the introduction of genetic information has reignited the belief that those individuals are in greater need of treatment, even compulsory treatment.” Though individuals may hold less blame than before, misconceptions and stigmas surrounding this type of illness persist.

“Once one has a diagnosis, or is perceived as having one, their perceptions as being able to open a bank account, make decisions on treatment, to marry again, etc., are significantly reduced.” Presumptions of incapacity to do daily life activities are what strips the seemingly common liberties that many enjoy from those who are given a psychiatric diagnosis. “People lose a lot of what we consider human agency,” which hinders both individual and societal progress by impacting how the community views those with psychiatric conditions and how those individuals—often forced to be institutionalized and/or have guardians make decisions for them—view themselves.

IV. Going Forward: A Societal Approach

Dr. Sabatello would “love people to have a nuanced understanding of psychiatric conditions, knowing that it is not a situation in which a single gene causes [it]” but that “many genes and other factors—such as environments, including socioeconomic status, social discrimination, social capital etc.—shape mental health wellbeing.” She simultaneously emphasizes the need for increased public awareness regarding the complexity of genetic and environmental influences on mental health and our collective responsibility to address those factors that impact individual well-being. Interdisciplinary collaboration offers promise for a future where collective efforts address the broader challenges affecting the many.

“We come from different perspectives. We speak in different languages.” However, through meeting each other in the middle and “highlight[ing] to one another what are the challenges, what are the barriers, and what are the concerns” relevant to our fields, we can glean a fuller picture of the issue and go beyond pure scientific discovery to identify feasible, actionable steps towards tomorrow. Strengthening society's view of its collective role in shaping the link between genetic essentialism and civil death of individuals with psychiatric conditions may prove itself as a promoter of equity and justice within the clinical space, legal realm, and everyday life.

Full citation of the article discussed–

Sabatello M, Chao A, Insel BJ, Corbeil T, Link BG, Appelbaum PS. Psychiatric genetic essentialism and stigma in child custody proceedings: public views. *J Law Biosci.* 2021;8(2):lsab026. Published 2021 Aug 26. doi:10.1093/jlb/lsab026