

Abstract

Exceptional Citizenship, Bounded Justice: Sickle Cell Disease in Brazil

Some Afro-Brazilian activists have strategically used a binary notion of race contrary to the Brazilian narrative of racial mixture in order to make claims to the State for health reparations for sickle cell disease (SCD). SCD is not a biological marker for race, but it can be considered a marker for ancestry from a geographic location where malaria is or was prevalent. The claims for health are legitimized by a biological and cultural distinction embodied almost exclusively by Brazilians with African descent. The presence of the S allele, thought to have come to Brazil via the forced migration of enslaved Africans, in addition to the ways in which blackness in Brazil are often defined by “markers of a distinctive black culture” (Kent and Wade, 2015) contribute to the ways in which biocultural citizenship is enacted for some Afro-Brazilians. This particular utilization of biology and culture contribute a new and distinct way to think about how race and skin color are used as tools of agency for diasporic communities. For this talk, I’ll argue that through particular biopolitical processes, activists have managed to successfully reconfigure their relationship with the State. In addition, I’ll discuss a new bioethical and biopolitical concept I am developing called Bounded Justice. Based on the empirical research that took place in Brazil, it frames how programs, technologies, and policies focused on justice-based notions of inclusion, do so without recognizing how the “benefiting” constituents have already embodied social exclusion.