

CONCEPT NOTE

NARRATIVE JUSTICE IN GLOBAL HEALTHCARE POLICY

Main sponsor: Permanent Mission of Kuwait to the United Nations

Civil society: SPSSI, the Psychology Coalition of NGOs at the United Nations

FEBRUARY 11, 2026 - 11am - 2pm ET

United Nations Church Center (UNCC), Second Floor, New York, NY; and remote

[Register for Zoom Attendance](#)

DESCRIPTION

Health disparities are deeply ingrained within healthcare systems across the UN Member States, particularly along the lines of race and ethnicity. Despite advancements in medical science, people of color continue to face profound inequities in diagnosis, treatment, and care, especially when it comes to rare diseases. These inequities are particularly pronounced in the diagnosis of neurological and neuromuscular disorders, where racial biases result in misdiagnosis, delayed treatment, and significant harm to patients.

Rare diseases, including autoimmune encephalitis, Duchenne muscular dystrophy, and other neuromuscular disorders, are often misdiagnosed, particularly in people of color, because their symptoms are frequently attributed to psychological causes - such as aggression, mental illness, or “poor decision-making” - rather than being properly assessed as underlying neurological or neuromuscular conditions. This issue is compounded by institutionalized racism in healthcare, where patients' experiences and concerns are dismissed, leading to unnecessary suffering, poor outcomes, and even fatalities.

The framework of *narrative justice* seeks to elevate the lived experiences of patients, particularly those from marginalized racial communities, and challenge the dominant medical narratives that silence their voices. By emphasizing the importance of listening to and validating patients' experiences, narrative justice addresses the systemic exclusion of marginalized groups from the decision-making processes in healthcare. This event will delve into how narrative justice can be applied in the diagnosis and treatment of rare diseases, and how failure to incorporate this framework exacerbates racial health disparities.

This side event will highlight how racial biases within healthcare contribute to diagnostic errors and delays, which have devastating consequences for patients' health. By focusing on the urgent need for accurate diagnoses and timely medical intervention in rare diseases, this event will advocate for a healthcare system that listens to and validates the experiences of racialized individuals. We will also showcase the ongoing work of scholars, healthcare providers, and community advocates who are committed to rectifying these disparities and advancing racial justice in healthcare systems.

OBJECTIVES

- To Address Racial Health Disparities in Diagnosis: Discuss how racial biases lead in healthcare leads to medical gaslighting and the dismissal of symptoms as psychological or personal failings rather than serious medical conditions - particularly in the case of neurological and neuromuscular condition - and the serious

health consequences of these errors.

- To Emphasize the Importance of Accurate and Timely Diagnosis: Discuss the physical, emotional, and financial costs of delayed or missed diagnoses in neurological diseases, both rare and common, and the dangerous impact that medical racism and dismissal can have on the lives and voices of marginalized people
- To Advance Racial Equity in Healthcare: Provide actionable steps for integrating racial justice into healthcare systems and other high-stakes and overtaxed systems to ensure the equitable treatment and outcomes for marginalized racial groups within those systems, with a focus on narrative justice and lived experience.
- To Foster Global Collaboration: Engage healthcare professionals, advocates, and policy-makers in a global discussion to share knowledge, build capacity, and develop strategies to address racial disparities, improve diagnostic accuracy, and rehumanize people in the systems they rely on.

LIST OF SPEAKERS

- **Keynote:** Sayantani DasGupta, MD, MPH – World-leading speaker and teacher on medical racism, author of *The Principles and Practice of Narrative Medicine*, and faculty founder of the master's program in narrative medicine at Columbia University
- **Major presentation:** Benjamin Saunders, PhD – Social psychologist and Associate Professor at LIU Brooklyn, and world-leading researcher on race-based system justification, a major underlying aspect of racist ideology
- SPSSI Representative and Intern Presenters: David Caicedo, PhD; Nallely De La Rosa; João Carvalho
- *Moderators: David Livert and Rachel Quintas – SPSSI UN Representatives, Committee Chairs of PCUN*