

Noma, Neglected Tropical Diseases and Human Rights Approaches

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Good morning. I am humbled to have been invited to speak on this panel, alongside the inspiring co-president of the first noma survivors' association and a distinguished humanitarian practitioner. I wish, if you allow me, to applaud the organisers for centring the voices of survivors in this event.

I am a human rights scholar. So, you may wonder: why would she speak at a side event of the World Health Assembly? Legitimate question... human rights fora are around the corner from our venue today. Neither I, nor the organisers have gotten the venue's address wrong.

I am here, *perhaps*, to remind us how important human rights approaches to neglected tropical diseases (NTDs) are, including to noma.

I will make two points in my intervention today. But I wish to foreground them in the following observation: Noma meets each of the four criteria of a neglected tropical disease. Noma:

1. Predominantly affects people living in conditions of poverty, and causes important morbidity and mortality in these populations, therefore justifying a global response;
2. Affects people living in tropical and subtropical areas;
3. Is immediately amenable to broad control;
4. And has been neglected in the field of research.

Evidence of this has been provided in the dossier submitted by Nigeria to the WHO. Noma's inclusion on the formal WHO list of NTDs would, therefore, be a recognition of *fact*.

As to my two points – they are drawn from research conducted with my brilliant colleague Alice Trotter at the University of York's Centre for Applied Human Rights.

First, human rights approaches to neglected diseases place an emphasis on certain substantive and process features that help us see the human beings affected by NTDs as *human beings*, not just through the narrow prism of their diseases.

As to the **substantive features**:

- A human rights approach clarifies that at stake are **legal, enforceable rights**, not merely needs or charity → Individuals are rights-holders!
- It also clarifies that at stake are **legal obligations of states** and **non-state actors**, not merely moral standards or social expectations that we address a disease.

As to the **process** features:

- **Participation** of rights-holders in decisions, which impact the realisation of their rights is the cornerstone of a human rights approach. Incorporation of human rights perspectives in NTD planning and programming, will be vital in ensuring that people affected by NTDs take up positions at the forefront of the agenda, that their lived experiences inform these processes at every level!
- **Accountability** of duty-bearers for the performance of their legal obligations is another important feature of the human rights approach. This need not always mean litigation, or subjecting states and other actors to ‘naming and shaming’ for failing to realise their human rights obligations. Accountability, however, can contribute to duty-bearers’ **ownership** of the process of realisation of human rights in relation to NTDs.

As an example, Nigeria’s efforts to address noma in country and by leading international efforts for its formal recognition as an NTD means that Nigeria has assumed accountability – such efforts can be seen as an indicator of a state’s progress toward the realization of its international human rights obligations.

As to my second point then: human rights approaches to NTDs, including noma, serve as a fundamental reminder that the NTD frame is (or should be) more than a medicalised one!

The WHO NTD classification recognises that diseases with significant morbidity and mortality are overlooked in the global health agenda *precisely because* they affect populations living in poverty. The over-medicalisation of NTDs – understood here as the application of exclusively or predominately medical knowledge to social problems – goes against the aim of establishing this category. At the very origin of the NTD frame, lies the recognition that structural discrimination within countries, and importantly within the global health and economic systems exists, and that this needs to be addressed.

Advocates and practitioners working on NTDs might be wary of me pointing out the structural, systemic aspects of NTDs. I, myself, have tried to avoid mentioning them many times over the last 14 years of working on noma. I did so because, far too often, whilst sitting in meetings with various officials I was told that: “the actual problem with noma is poverty”. This acknowledgement did not make me rejoice – because it was delivered as a statement of the *futility* of even attempting to address noma. The story went: “we can’t solve poverty, we therefore should not try to work towards noma’s prevention, by for example, including it in the WHO NTD list”. A fatalist fait accompli usually delivered – if I may confess this in a public forum without causing offence – by men from the Global North in positions of power. My response to such statements has been to first point to how easily noma could actually be treated if caught early on, and second, to emphasise the legally binding human rights duties states have to address it.

Today, and looking at social science and medical research on other NTDs, such as snakebite and leprosy, I will submit that we *must* consider the structural aspects of neglected diseases *alongside* operational efforts such as the WHO NTD framing.

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Allow me to conclude with the following passage from a recent chapter co-authored with Alice Trotter and published in a forthcoming volume on Global Health Justice:

“The human rights and NTD frames of noma need to find ways to become increasingly compatible because their individual success lies in their complementarity. Not only is it possible for these two overarching framings of noma to coexist, but we move to suggest that translation of this coexistence into policy and action will be necessary to the long-term advancement of the agenda. Doing so will go some way toward recognising that ... it is no longer possible [if it ever was] to, ‘separate what is medical from the social, the economic, the cultural, and the political’.” [citations omitted]

Thank you.