

Let them talk and we listen: what are diseases of neglected people?

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This article is a reflection from a person with lived experience of leprosy, who has been working as a global advocate and champion for the rights of persons affected by neglected tropical diseases for the last decade. Synthesising learning from the collection of pieces included within this special supplement that are written from the perspective of people affected by neglected tropical diseases, I argue that it is time to centre the lived experiences of people affected by neglected tropical diseases. These are diseases of neglected people, and it is now time to let them talk while we listen.

Cet article est une réflexion d'une personne ayant vécu la lèpre, qui travaille depuis dix ans en tant que défenseur mondial des droits des personnes touchées par les maladies tropicales négligées. En synthétisant les enseignements tirés de la collection d'articles inclus dans ce supplément spécial et rédigés du point de vue des personnes touchées par les maladies tropicales négligées, j'affirme qu'il est temps de centrer les expériences des personnes touchées par les maladies tropicales négligées. Ce sont des maladies de personnes négligées, et il est temps de les laisser parler pendant que nous les écoutons.

Este artículo es una reflexión de una persona con experiencia vivida de la lepra, que ha trabajado como defensor mundial de los derechos de las personas afectadas por enfermedades tropicales desatendidas durante la última década. Sintetizando el aprendizaje de la colección de artículos incluidos en este suplemento especial que están escritos desde la perspectiva de las personas afectadas por enfermedades tropicales desatendidas, sostiene que es hora de centrar las experiencias vividas por las personas afectadas por enfermedades tropicales desatendidas. Estas son enfermedades de personas desatendidas y ha llegado el momento de dejarles hablar mientras nosotros escuchamos.

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In 2010 I was diagnosed with leprosy in Paraguay, the country where I am from. I was fortunate to be diagnosed and treated early. After the initial symptoms went away, I never developed any complications or impairments caused by the disease. I also never felt discriminated against, which unfortunately is not true for most persons affected by leprosy and other diseases of neglected people (DNPs). I never lived in poverty, I had access to good education, housing, job opportunities and other privileges.

Earlier this year, the mosquito-borne disease of Chikungunya made its rounds through Paraguay and affected a lot of people; my wife and I also fell prey to it. Even although we were able to access appropriate medical care, the pain, the fever and discomfort took weeks and even months to subside. My wife continues to have residual pain that often interferes with her activities.

A few months later our family dog fell ill and was eventually diagnosed with leishmaniasis. It took three persistent visits to the veterinarian to receive proper attention and diagnosis. The treatment consisted of daily injections for a month and a combination of pills, which we could manage from home. It has been several months and she is doing better, but she will most likely never get her health back fully. This situation was very stressful for our entire family (including two other dogs that thankfully did not contract the disease).

As I started writing this article, my son was sick in bed for several days with dengue symptoms. It turned out to be an unspecified mosquito-borne disease, but it took a toll on him and on us as a family. All of this, despite our possibilities of accessing quality healthcare, resting when needed, good nutrition, adequate housing and everything needed for a healthy life.

Imagine a person living in a remote village, with lack of access to education, job opportunities, information, adequate housing, healthcare and proper nutrition. Having a DNP will have a much greater impact on their lives and their families, including on their mental well-being.

The impact of DNPs is illustrated in the contributions to this special supplement written by persons affected by these diseases. They show the burden on their physical and mental health and the close connections to social and even financial consequences. Life is very complex for all of us; however, persons affected by DNPs often have added layers of complexity, difficulty and challenges.

Perhaps some of you are wondering what on earth DNPs are. I intentionally decided to stay away from the term ‘neglected tropical diseases’ (NTDs) and chose to use ‘diseases of neglected people’. As has been pointed out by Dr. Arianne Shahvisi (in her 2019 keynote speech at the 2019 Conference of Network of NGOs working with NTDs), it is not the diseases that are neglected. People are neglected! Most of these people are living in the Global South, in contexts of poverty and with inadequate living standards. They are the ones that have been and are still being neglected. The fact that leprosy was very widespread in Europe during the Middle Ages and that it was basically eradicated before the bacteria responsible was identified, points to the crucial effects of improved nutrition and living conditions.

This is why it is important that we centre persons affected in our conversations about DNPs. By ‘centring’, I do not mean talking about them, but talking with them. Even better: let them talk and we listen. Let them explain to us what it is like for a woman to have leprosy in a village in the mountains of Nepal, or for a man affected by river blindness in Liberia, or a community affected by Chagas disease in the Americas.

While it is important to hear what they have to tell us about their realities, this is not where their participation and involvement stops. As described in their contributions, persons affected by DNPs are very invested and capable of improving their own lives and the lives of their communities. This goes even beyond the local area to regional, national and international involvement.

‘Having experienced the disease, disability and associated discrimination, persons affected by NTDs have a unique voice and perspective, they bring passion to the work and take the programs closer to the communities they are designed to benefit.’¹ Therefore, if we want to truly understand DNPs or NTDs, we need to put persons affected by these diseases at the centre, listen to them and also make sure that they are part of every decision that is made about them. There are countless examples of individuals, families, communities, formal and informal organisations, on local, national and international levels, that are already making the difference. Persons affected by DNPs are not the problem; lack of an adequate living standard is. The involvement of those affected by DNPs is crucial in progressing towards solutions.

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Reference

- 1 NNN Statement of Commitment to the Participation of Persons Affected by NTDs. Available at: <https://www.ntd-ngonetwork.org/nnn-statement-of-commitment-to-the-participation-of-persons-affected-by-ntds> [accessed December 19, 2023].