

Disability Voices paper (Sept 2023)

# Understanding Stigma

## Listening to people living with Neglected Tropical Diseases (NTDs) in Nigeria



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## What is stigma?

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**“Loneliness is deadly, when you associate with others you feel happy, and your mind is calm and heart at rest. No more joy and happiness in our lives because of the segregation and stigmatization” Woman living with leprosy.**

Stigma is a negative set of beliefs about a group of people with specific characteristics<sup>1</sup>. Stigmatising beliefs and associated behaviours stem from ignorance or a lack of awareness and fear, which in turn drive prejudice, discrimination and exclusion of people with those characteristics.

Social stigma creates barriers to participation in all areas of life and perpetuates cycles of poverty. It negatively impacts people’s quality of life and can prevent them from playing a full role in society, even undermining the effectiveness of targeted interventions if people are kept out of sight by their families or feel too fearful or ashamed to come forward and participate. This increases the likelihood of dependency on others, of having lower incomes, poorer health and achieving a lower level of education. There are over 1 billion people with disabilities in the world, often affected by considerable community stigma and resultant discrimination and exclusion. This is a huge waste of human potential as well as an abuse of people’s basic rights.

High levels of community stigma surround many neglected tropical diseases (NTDs), particularly those that are highly visible such as leprosy and lymphatic filariasis. These conditions, when left untreated, can result in disabling symptoms including nerve damage and paralysis, loss of fingers and toes, swelling due to lymphedema and other visible changes in skin condition such as lesions or thickened skin<sup>2</sup>.

In this paper we hear from people living with leprosy and lymphatic filariasis in Benue State, Nigeria. Their testimonies were gathered through focus group discussions and key informant interviews conducted as part of the Mind Skin Link project in Nigeria<sup>3</sup>. They disclose the harmful impacts that living with such highly visible and stigmatized conditions can have on all aspects of their lives and wellbeing. Their testimonies are hard to read, but are important to hear and reflect on, particularly for those of us working to improve inclusion in NTD services. Contributors to the paper make it clear that stigma reduction must be central to our efforts to support greater inclusion. The Mind Skin Link project listened and responded with a package of interventions to identify and address mental health, anti-stigma and wellbeing needs for people with visible skin NTDs.

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<sup>1</sup> Kishore, M., Hussain Al-Haboubi, Y., Tseng, P-C., Semrau, M. and Eaton, J. (2022) *Mental Health, Stigma and Neglected Tropical Diseases: A review and systematic mapping of the evidence*, in *Frontiers in Tropical Diseases*, 11 October 2022, Volume 3 - 2022 <https://doi.org/10.3389/fitd.2022.808955>

<sup>2</sup> WHO Fact Sheets are good resources for further information on NTDs. For example: [Lymphatic filariasis](#)

<sup>3</sup> A summary of the project is available in this CBM UK news item, Sept 2020, at the following link [“The Mind Skin Link: new project will improve mental health and tackle stigma for people with Neglected Tropical Diseases” - CBM \(cbmuk.org.uk\)](#)

## What do people tell us about the stigma they face?

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Harmful community attitudes and behaviours may be expressed by individuals or groups within a population and include false assumptions and beliefs that position people as dangerous, bad luck, or shameful. Participants in the Mind Skin Link project described this **public humiliation** in the following ways:

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**“They curse you; mock you daily”** Woman with leprosy.

**“It was even so bad that the people had to be announcing themselves unclean so that people can know you are coming”** Man with leprosy, now living in a supportive community.

**“People look down on us and castigate us that it is our behaviour that has resulted to this ailment we have. We get all forms of embarrassments and humiliations”** Woman with leprosy.

**“This sickness has made me ashamed of leaving the house as children usually make fun of me. This makes me cry a lot and makes me sad”** Woman with lymphatic filariasis.

**“Many times, people look at my legs before they see my face and begin to talk about me, this makes me so sad and unable to be at peace”** Woman with lymphatic filariasis.

**“I also have been disgraced by this sickness as I am treated like someone that is worthless”** Woman with lymphatic filariasis.

**“I feel sad. I go through lots of humiliation, shame, and stigmatization”** Woman with leprosy.

**“Every single day of my life I get reasons to be ashamed and humiliated. Too many unpleasant things”** Woman with leprosy.

**“...they think I stepped on something in front of someone’s house to get this disease”** Woman with lymphatic filariasis.

**“Sometimes when I go to places where people are, they will be casting me as if I am not a person”** Man with leprosy.

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**Stigma and shame is often extended to family members and friends**, often resulting in relationship breakdown and social isolation. People shared the following experiences:

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**“My mother is always praying for me and my children, but some people have been accusing her of being responsible for this sickness”** Woman with lymphatic filariasis.

**“Some people have even told my mother to leave my father and that we are a family of leprous people but none of us has it”** Caregiver.

**“Even my husband complains about me and now we have been fighting very often which is not the way it used to be”** Woman with lymphatic filariasis.

**“I am not even allowed into my mother’s house”** Man with leprosy.

**“My entire family has turned their back on me, even my children have rejected me”** Male with leprosy, living in a supportive community.

**“...this disease has made things different, when children come with their needs and demands and there’s no provision, they disregard and don’t see you as a parent anymore. Even their attitude towards you is so bad”** Woman with leprosy.

**“Many people don’t even want us associate with them because we are caring for leprosy patients”** Caregiver.

**“My husband’s family have not been supportive as they say I should die”** Woman with lymphatic filariasis.

**“Our community members lack pleasure and joy to associate with us”** Woman with leprosy.

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**People often internalize these negative attitudes, and this contributes to self-stigma, feelings of shame and self-consciousness.** The following statements express the damage that internalized stigma has on people’s emotional wellbeing:

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**“My problem now is that I'm down, even my mind is not as it used to be”** Man with leprosy.

**“...even my close family members did not want to associate with me, and this has bothered my mind greatly... I also feel ashamed to go close to them”** Man with leprosy, now living in a supportive community.

**“It affects me ...when I look at my body I feel like an outcast”** Man with leprosy, now living in a supportive community.

**“When I walk, I am conscious that people are looking at me”** Woman with lymphatic filariasis.

**“My wife used to be unable to meet with people in a gathering because she always felt they were looking at her legs, so it affected her psychologically”** Caregiver.

**“It makes me not to even have confidence in myself”** Man with leprosy, now living in a supportive community.

**“...we ourselves don’t feel confident going to where people are. It makes me feel embarrassed and uncomfortable”** Man with leprosy.

**“Sometimes, I think of going out, but I do not because of the shame of being among other people”** Woman with lymphatic filariasis.

**“Sometimes, I feel like one that is mentally ill because of this illness and now I have palpitations very often and feelings of sadness, even this morning, I cried a lot. When people asked me, I told them I just want to die and end this suffering”** Woman with lymphatic filariasis.

**“I have been wishing for death but it’s not coming. Even church, I don’t go anymore and not because anyone has stopped me but due to fear of people seeing me, I have chosen to stop going”** Woman with lymphatic filariasis.

**“This makes me mentally unstable and terribly sad. I can hardly sleep at night, I cry out”** Woman with leprosy.

**“I believe that we are a waste and nobody cares about us”** Woman with lymphatic filariasis.

**“When you think about this, you can hardly sleep, you are never mentally sound nor at peace. When all these happens, I ask God in prayer, why won’t you just take away my life rather than allowing me to see this bitter life”** Woman with leprosy.

**“I feel like life has disgraced me in front of people around me, I am always ashamed to go to where people are”** Woman with lymphatic filariasis.

**“...now I am wishing for death. This sickness has made me ashamed of going to where people are, I tie my wrapper to cover my legs. I don’t attend the meetings I used to anymore due to the shame I feel”** Woman with lymphatic filariasis.

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### **Box 1: The importance of family love and support in the face of stigma**

It is important to remember that people’s experiences differ and many family members remain supportive in the face of social stigma. The following statements give a flavour of just how important caregivers and community support networks are to people and their wellbeing:

“As for me, I am really loved in my family... my family has been supportive and hoping this sickness will end” - Woman with lymphatic filariasis.

“For me my family has been helpful as they even made trouble with my husband’s people accusing them of inflicting me with this disease and took me back home” - Woman with lymphatic filariasis.

“So many people who see me are merciful towards me and help me a lot, I am thankful about this. Walking is usually an issue, but children always give me lifts each time they see me walking, some even when they don’t pick me, they sympathize with me knowing that I was not [always] this way. So, they are always merciful towards me” – Woman with leprosy.

“Also, for me, they do not stigmatize me in church, the people talk to me well when I am in church” - Woman with lymphatic filariasis.

**Public stigma undermines the visibility of people with disabilities in society.** People often isolate themselves as a result of self-stigma and internalised feelings of shame. Families or community members may keep people with disabilities or disabling conditions out of public sight (for example, hidden in their homes or even locked up), or ignore them in public places. People described feeling shunned by their communities and isolated:

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**“Mostly, when people are gathered or talking and I come around, everyone goes away so this makes me stay away from people”** Woman with leprosy.

**“I noticed that some people I thought were close to me have been avoiding me”**  
Woman with lymphatic filariasis.

**“This disease has separated me from people”** Woman with leprosy.

**“...people are looking at you in a way that says don’t come close”** Woman with lymphatic filariasis.

**“They look at me as if I am a stranger to them, even strangers are treated better”**  
Woman with lymphatic filariasis.

**“People’s actions have prevented me from doing things greatly because the people I used to move with and do things with have left me now”** Woman with lymphatic filariasis.

**“...they even become ashamed of laying their eyes on me. They all avoid and run away from us”** Woman with leprosy.

**“It seems the whole world has abandoned and rejected me”** Woman with leprosy.

**“Before now in church, people will naturally move for me to share a seat with them but now they don’t want to me to share a seat. They expect me to go and sit at the back of the church so that even when they are preaching, I can’t hear what the pastor is saying”** Woman with lymphatic filariasis.

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**Stigma can impact how people interact with public services and facilities** such as accessing community water points, health centres or attending school. It can inhibit people in coming forward and asking for help, or in going to health centres for treatment, or attending school. People spoke about how stigma has driven their exclusion from public services and resources:

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**“When I am with people, they chase me away from where they are and refuse to associate with me. Even in school, I don’t have friends because everyone stays away from me”** Woman with lymphatic filariasis.

**“This sickness prevented me from going to school and also has made me miss a lot of things either through inability to walk around due to pain or shame from people staring at me”** Woman with lymphatic filariasis.

**“I would have gone farther in my education now compared to the way I am”**  
Woman with leprosy.

**“Even the borehole near me I can’t fetch from there or even the well because the people won’t allow me”** Adult with an NTD.

**“For me, because of the stigma, I feel ashamed to go to the well so some girls living around me help me fetch water”** Adult with an NTD.

**“I had to go to the river because my well dried up. I noticed people pushing away water from where I stood”** Woman with lymphatic filariasis.

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## **Stigma impacts an individual's basic rights.**

The realisation of people's basic rights is constrained by public stigma and self-stigma. This section gives a brief flavour of the multiple barriers that stigma creates to limit respondents' full and productive lives.

Stigma impacts on a person's right to a full family life:

**"All my age mates and peer group are married but I am not. This disease has disrupted my entire life"** Woman with leprosy.

**"Even my husband has gone to marry someone else and even when my husband brings small money for me to look after our child, his new wife will ask why he is giving a diseased woman their money"** Woman with leprosy.

**"I met a man who told me that he likes me but he heard this disease I have runs in my family and he is afraid that his children may also get infected if he marries me"** Woman with lymphatic filariasis.

Access to public services is impinged when staff hold discriminatory attitudes towards people living with stigmatised conditions:

**"...even the health workers used to discriminate against us"** Man with NTD.

Stigma limits people's access to gainful work and livelihood opportunities:

**"When I was barbing hair before I came to this place, I had wounds in my hands so customers will see the wounds and ask for someone else to barb their hair and ignore me"** Man with leprosy.

**"This disease has hindered me from working"** Woman with leprosy.

**"I had to even stop trading as no one was patronizing me anymore"** Woman with leprosy.

**"I work here in this hospital but since my diagnosis of this disease, most of my colleagues are against my working here"** Woman with leprosy.

**"I started a restaurant, then people started stigmatizing me and saying how can you be eating in that women place and so people stopped patronizing me, then I had to stop the business"** Woman with leprosy.

Stigma also creates barriers to people's active engagement in politics and take up of leadership roles:

**"In the church, I used to be the women leader for 3 years but now they told me I can't lead them anymore because of my situation"** Woman with lymphatic filariasis.

**“I used to fry icefish and I was the leader of that association before this disease but since I became sick many people have avoided me and because of this I also had to leave the association and step down as their head”** Woman with lymphatic filariasis.

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## **What do people tell us they need?**

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When asked, people identified their immediate practical needs as their highest priority. This was not surprising as living with stigmatized NTDs has a significant impact on people’s ability to earn a living and access services. This section gives a sense of these priorities – namely having their own money and improved access to treatments, including transportation to treatment centres.

People need money:

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**“What will help me in this world to improve my life is money because if one has money even when you are down and can’t work, money can bring everything that you want to you and this will make you feel like you are a human being”** Man with leprosy.

**“If you have enough money, you’ll buy good food for you and your family and the person supporting you. But if there’s no money, you’ll fare worse”** Man with leprosy.

**“I cry to God and say He should just take my life away because I don’t have any means, no money to afford any treatment at all”** Woman with leprosy.

**“Money sorts out most of your problems and gives you peace of mind”** Man with leprosy.

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People need access to treatments:

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**“...if you can help us recommend a place we or our loved ones can go for treatment”** Male with leprosy.

**“I have asked that God will give direction to get drugs to help treat this sickness and if God does this for us, I will be happy. I believe that once a cure is gotten, all other things in my life will go well”** Woman with lymphatic filariasis.

**“I know the ultimate treatment will be provision of drugs to help heal this sickness that we have so if there are drugs, they will help us a lot”** Adult with NTD.

**“There are some people that live very far so getting here can be a problem”** Caregiver.

**“...if there are provisions for transport money then it will help”** Caregiver.

**“If you people can put mobile clinics close to us and we do not have to go far to get treatment, it will go a long way to help us because there is no money so if it is**



**close to us we can even walk there to take the Mectizan”** Woman with lymphatic filariasis.

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## **How does understanding stigma help us deliver better services and interventions?**

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When people are asked what they need it is unsurprising that they identify critical resources (money) and support (treatment). Income generation and access to services are key. However, we know that stigma undermines the provision of services to support NTD-affected people and their uptake of treatment. Providing money and treatment alone is not enough as these do not reduce the exclusionary effects of self-stigma, social isolation and discrimination in key services and institutions. The Mind Skin Link project recognised the centrality of stigma on people’s mental health and trained health staff to recognise signs of anxiety and depression among skin NTD-affected people. Psychological support was offered to support wellbeing and counter extremely damaging impacts of stigma.

The lived experiences of stigma curated in this paper confirm the importance of taking mental health seriously in supporting NTD-affected people, and point to three stigma reducing priorities:

### **1. Awareness raising is important to demystify disability.**

Positive, direct contact with stigmatized people can discredit stigmatising beliefs, alongside better information about disability and disabling conditions to reinforce understanding and compassion. Communities, families and duty bearers need to understand the harm that stigmatizing people causes and stop:

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**“I want to ask what can I do to enable to walk side by side with other people again because now I am always scared”** Man with leprosy.

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In the case of skin NTDs, awareness raising needs to include developing a better understanding of how the condition was contracted and the ongoing transmission pathways. A more accurate understanding of these conditions and how they can be treated will help reduce self-stigma, concerns of families and the wider community. Awareness raising must include training and support to public service staff to facilitate better service provision and treatment uptake. The impacts of this can be transformative:

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**“Words of encouragement and the way they have attended to me has made me happy”** Adult with NTD.

**“I feel a lot better even though I haven’t been given any drugs yet. Today one of the doctors spoke to me and even shook my hand”** Adult with NTD.

**“I didn't even want to come to this hospital. But now, the doctors here have reduced the neglect a lot”** Man with leprosy.

**“The little interaction with people in the villages that are very sick and after the scheme training, they have reasons to live and be happy and they feel people care about them in the villages too”** Service provider.

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## **2. Increase the visibility of stigmatized people as productive members of their community.**

Increased visibility and the normalising of people with disabilities and disabling conditions is essential to undermine negative stereotyping, fear and shame. Interventions need to support people to be active, productive members of the community, so that they are recognised as people with dreams and hopes for their future like anyone else.

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**“If someone wants to help me, it's not when they give me food that they've helped me, it's when they give me a source of income so that even when the food finishes, I can still earn something for myself”** Man with leprosy.

**“To see my dreams come to pass and to take care of my children to a point where they can become something tomorrow and to get well because when people treat me in a certain way, it makes me feel bad. What will improve my life as a hair stylist, by providing equipment for me to help me in my business”** Woman with lymphatic filariasis.

**“That is why my focus is on going to school and I am studying community health, so my goal is to open a hospital when I finish school”** Woman with lymphatic filariasis.

**“It will be good if we the leprosy patients also find ways to enable us to feed ourselves and families. This will make me also feel like a human being”** Man with leprosy.

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## **3. Peer to peer support and being part of a support community can counter self-stigma and improve mental wellbeing.**

Self-help is empowering and healing. Self-help groups are a good way to provide peer to peer support and help re-establish people within their communities.

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**“For emotional support, to take away certain feelings from me such as fear of failure and to feel free when I am in the midst of people and not feel condemned”** Woman with lymphatic filariasis.

**“But inside here, both those who have this disease and those who don't, we do things together, we eat together. There's no stigma here at all. We even get help sometimes. This has made us not to see much differentiation”** Man with leprosy.

**“Talking to us has really helped us by comforting us with your words”** Women with leprosy.

**“Now, I go to sit with other people and chat and this takes my mind off things so I feel comforted”** Adult with NTD.

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## **What is the impact of reduced stigma?**

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Treating people respectfully gives them hope. The people we talked to through the Mind Skin Link interviews and focus group discussions reported this hope in terms of reassurance, comfort and joy at not being forgotten. Feeling better understood and less isolated brings manifold positive benefits, including improved family relationships and even heightened government engagement. Ultimately, this kind of change plays a fundamental role in enabling the full participation of people with disabilities in all areas of society.

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**“The interaction between we and your people has given me some comfort because before now, it was difficult for anyone to sit and talk with us”** Man with NTD.

**“The help you rendered us to enable us to go back to our places of residence after we came here also helped us a lot. There is a lot of difference for me because now I feel that the Government is remembering us with leprosy too that is why they have sent people to talk to us”** Man with NTD.

**“This service has helped us because we are happy that you are interested in our health, how we work, how we feed and do things in life and how we feel in the inner most part of our hearts. I really appreciate that gesture, so thank you”** Man with NTD.

**“By associating yourselves with us, it has made us feel that we have not been forgotten and people are still with us”** Man with NTD.

**“Your coming has made me feel that you people are thinking about us. Secondly, the way you talk to us in a nice way also gives us joy in our hearts”** Man with NTD

**“The person that I have been taking care of has changed a lot since we started visiting your people here. He used to get angry very easily but since we started coming here that has reduced”** Caregiver.

**“My wife used to get angry and be so impatient but now things are getting better so I appreciate you all. The health workers are respecting them and giving them drugs that are helping them”** Caregiver.

**“I have seen a lot of difference because my mother used to say she would rather die but now the doctors have told her what to do and she praised them a lot. She says she doesn’t want to die anymore and will continue to come here for treatment”** Caregiver.

**“I really felt deserted at that time that I wished for death, so that my relatives will be ashamed that they left me to die, but when I spoke to you about my problems, I felt better when I went home. The treatment they have given us, and the talk is great comfort to me”** Woman with leprosy.

**“I believe that words of encouragement are a form of medication because when you talk to someone, they feel comforted, so for me the encouragement is even more important than the drugs”** Adult with NTD.

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## Conclusion

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We all benefit from living in inclusive societies that respect human rights and dignity of all. People with disabilities have the right to be treated with dignity and to fulfil their potential. We have heard just how pervasive social stigma is, and in order to support people with disabilities and disabling conditions to access services, claim their rights and live fulfilled lives, we cannot ignore the reality of how they are being viewed and treated in their communities, by service providers and other duty bearers. We are very grateful to the participants of the Mind Skin Link project in Nigeria for sharing their lived experience and helping bring home the message that holistic, stigma reduction must be at the heart of all we do if we are serious about breaking the poverty-disability cycle and achieving disability inclusive societies.

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There is an official research page for the Mind Skin Link project on the COR-NTD portal at <https://www.cor-ntd.org> Please note, the Bill & Melinda Gates Foundation is the Open Access route for researchers to request access to the de-identified data – and (if approved by the ethical consent board) to the original identifiable data.

For further information please contact [Advocacy@cbmuk.org.uk](mailto:Advocacy@cbmuk.org.uk)