



REDRESS

Reducing the burden of
Severe Stigmatising Skin Diseases

Centring lived experience - peer advocates and peer support groups foster social inclusion, community participation and mental wellbeing to generate a network of persons affected by NTDs in Liberia



Peer Support Group, Margibi County

Summary / Synopsis

People affected by skin NTDs are at the heart of REDRESS' approach to person-centred care. Peer support groups, also known as self-support or self-help groups, are formed by individuals affected by similar challenges, providing mutual guidance and support in various aspects of wellbeing, including mental health, economic empowerment, advocacy, and self-care (WHO 2020). Peer support groups often evolve into networks of persons affected. However, evidence on their establishment through routine health systems structures is limited as, to date, such interventions have largely been driven by the non-governmental sector. Recognising a gap in inclusion of persons affected in shaping NTD programs in Liberia, REDRESS explored the best approach to strengthen a network of peer advocates, including establishing peer support groups. Peer support groups and peer advocates play a key role in empowerment in health education, livelihoods as well as peer support and advocacy. Networks and connections between participating people resulted in improved mental wellbeing, inclusion and participation, self-esteem and reduced stigma.

Background

Why is there a need to establish peer support groups for people affected by NTDs?

Neglected Tropical Diseases (NTDs) often affect individuals within marginalised communities, causing significant physical and psychosocial health issues, stigma and isolation. Historically, NTD interventions have focused on biomedical support and lacked focus on broader support needs and the perspectives and priorities of persons affected are rarely considered. Networks of persons affected by NTDs are a critical resource in demanding rights and accountability within endemic settings, yet minimal evidence exists on the best way to develop and establish such networks. One strategy is thought to be through the establishment of peer support groups that not only meet the self-care needs of persons affected, but that evolve into strong advocacy platforms. To date, peer support groups have largely been established in partnership with non-governmental organisations (COUNTDOWN 2021; Chowdhury et al, 2022), and further understanding on how to create and engage with such platforms within routine health service delivery is required.

Within REDRESS, prior to the intervention, persons affected by skin NTDs highlighted that:

- ✓ Pervasive forms of stigma - internal, external, and anticipated - lead to rejection and isolation within families and communities.
- ✓ Stigma had negative impacts on mental wellbeing and persons affected felt isolated and alone in their illness journey, leading to loss of livelihoods and familial support.
- ✓ Social support from the community, faith-based providers and other persons affected were highlighted as enablers to seeking care and promoting positive mental wellbeing.

Consequently, we worked alongside persons affected by skin NTDs in Liberia to establish peer support groups that were linked to and supported by health systems infrastructure with a view to creating an engaged network of persons affected by NTDs in Liberia.

What was the impact of REDRESS interventions?

Impact of Peer Advocate Training

- Peer advocate training equipped persons affected with knowledge about their condition, communication skills, and the ability to support others facing similar challenges by working together to establish peer support groups.
- Peer advocates built confidence in speaking through effective communication techniques to share their experiences and advocate for their rights within communities, dispelling myths and misinformation, and reducing stigma associated with NTDs.
- Peer advocates became knowledgeable about available treatments, how to access healthcare services and engage more actively in their healthcare journey. This knowledge facilitated peer advocates to play a key role in motivating others with similar conditions to seek care at health facilities and follow treatments.

"I really find the training so important to me. Because by your coming here, you really educated us to know much about our own problem. Before if we had this problem, we were going to country doctors and our problem will increase. So now we have found the right road."

Person affected, FGD post peer advocate training, Grand Gedeh County

Impact of Peer Support Groups

Peer support group members reported improved understanding of their condition and acquired better skills in self-management; this resulted in improved physical outcomes, for example reduction in wound size or healing of wounds.

- Peer support groups have had a positive impact on the mental health of persons affected through sharing experiences and connecting to others.

"I really used to sit lonely in my case yeah I used to be discouraged of my case sometimes when I sitting in a room I would be crying alone I would be all kinds of bad bad feelings would be coming to me but through this Peer Support Group at least sometimes while people talking to me when y'all get around us like that comforting us, talking to us at least I can feel fine in my case yeah that's why I decide to join the Peer Support Group."

PSG member, female, Margibi County



"The photo you see here you can see the hands are together. We are as a sick people. People came to our rescue. We need to love each other and hold each other. We need to love each other and always be there for each other. Because we are already found ourselves in, this is a stigma. There is nothing that we can do to cancel this. It has already happened in our life and we moving with it. But through you, through me through other people we can make it. So let's love each other care for each other and be one."

Alice, peer support group member, Lofa County

- Being a member of the peer support group improved the self-confidence of members, with many highlighting the success of their treatment and the decision to share this with others with similar conditions to counsel them as well as encourage them to attend the health facility.

"What I learned from there is that we need to comfort one another. It made others feel that we are part of the society. When we meet in our meetings, we talk to one another, we comfort one another. That's the only thing I learned there. It makes me feel to fine, by then helping all to do something for ourselves."

Peer support group member, female affected by lymphatic filariasis, IDI, Grand Gedeh County

- **Increased participation and acceptance** were key impacts across. Participants shared their personal journeys from internalised stigma to increased participation in their household and community, for example being able to eat with others. Although stigma still persists and more community awareness is needed, many expressed an improved sense of self-worth.



"...You can see the whole group putting their hands in one pan eating, sharing, and in fact fighting over it I'm happy it shows happiness. This is what I want to be. This is how I want to live. This is how I want for people to come around me. I don't want to always continuous living stigma to myself. I want to be among people we ourselves we can create our own stigma apart from the people out there. Because if you say, because people not coming around me, let me just keep nervous or let me just keep by myself that alone is a burden by itself I love to be among people. I love for people to eat with me. I like to share food. So the photo shows what? Happiness, love. I love this."

Alice, Lofa County

- **Self-directed income generation activities** such as soap-making enabled group members to generate income and alleviate financial challenges. Members took various roles, from managing finances, purchasing materials, overseeing production, selling the soap, and reinvesting profits back into the business for sustained growth. Participants stress the importance of financial transparency and accountability within the group and ongoing engagement with group leads to plan for sustainability as essential.



[Watch: Peer Support Group Video](#)



"This picture represents the support and help that REDRESS is giving to the affected people. REDRESS send us money that we should use and be able to help ourselves. This money, if we divide, it will finish. But the only thing we need to do is to try to put it into at least business that small money will be there all the time to help our members. So, we want to really play the role of making it important to ourselves. The key message is if you get this foot, if you get this problem, whether it is on you or it is finished, once you come to us and we know you, you will be part of this help."

Nathaniel, co-chair of peer support group
Grand Gedeh County



"REDRESS gave us \$500 US dollars for the peer support groups to help us to make soap so that we can be able to learn how to fix soap for everybody... So REDRESS make us to be united to fix soap together today. So that's we can sell it."

Mavolo, peer support group member, Lofa County

- **Peer counselling by group members and peer advocates was accepted and a key strength of the support group model.** Not all group members are always able to take on this role and it should not be a pre-requisite of engaging within the support group.
- **Peer support groups across counties are connected by key advocates and community advisory boards,** enabling them to come together and work toward registration as an official organisation of persons with disability. Exposure to networks of persons affected outside of Liberia facilitated this process and galvanised action.

How did REDRESS establish peer support groups?

Our approach was guided by and inclusive of people affected by NTDs. Recognising their own skills and capabilities they supported us to co-design an intervention that involved their participation at various levels to support and sustain a peer-support intervention:

- ✓ 60 peer advocates (persons affected) were trained within routine programme training cascade structures in:
 - awareness of NTDs, how to recognise symptoms and refer other persons with skin NTDs,
 - basic psychological support and stigma reduction adapting the Look, Listen, Link tool through visual images and adapted language setting up peer support groups (PSGs).
- ✓ Six peer support groups were established across the three counties to encourage geographic accessibility for all persons-affected. Support groups also had sub-cells that met more regularly. Groups self-identified roles, e.g. chairperson etc., and received ongoing regular support from the county NTD focal person. Through time there were less frequent support visits from county health team focal persons and increased dialogue and collaboration between groups across counties facilitated by the lead for the network of persons affected.
- ✓ Peer support group members identified and invited others with similar skin conditions to join their group. The groups were intended to provide space for experience sharing and to learn about their condition.
- ✓ Groups were provided with seed funding and chose to make soap, in order to generate revenue for the sustainability of the group.
- ✓ Some peer support groups took their own initiatives, collectively identifying their priorities. Some groups in Lofa worked together to host a radio campaign to raise further awareness about skin NTDs within their community.
- ✓ **Formal registration of NTD network as an organisation for people with disabilities:** Emmanuel Zaizay (network lead) attended the non-governmental network for NTDs conference and was introduced to an international network of peer advocates IDEA [International Association for Integration, Dignity and Economic Advancement]. He delivered a presentation on REDRESS's person-centred approach in the treatment of individuals with severe stigmatising skin diseases and was inspired to support the formal registration of a network of persons affected by NTDs in Liberia with support and advice from the IDEA network.





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