



REDRESS

Reducing the burden of
Severe Stigmatising Skin Diseases

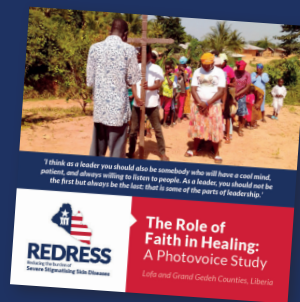
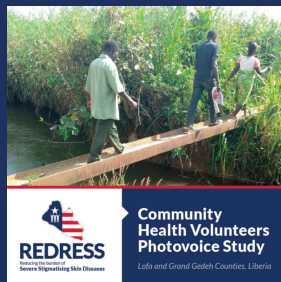
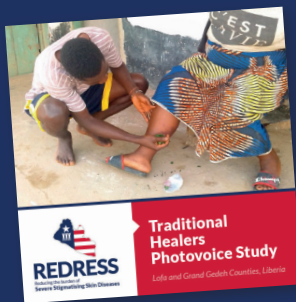
Community Health Assistants Photovoice Study

Lofa and Grand Gedeh Counties, Liberia

Community Health Assistants Photovoice Study

Neglected Tropical Diseases (NTDs) affect around one billion people globally, often the most poor and marginalised groups in society.

For many persons with severe stigmatising skin diseases (SSSDs) such as leprosy, buruli ulcer, yaws, onchocerciasis, hydrocele and lymphedema, lack of access to effective services results in significant physical, financial and psycho-social impacts. Delayed diagnosis and disease progression cause greater and largely irreversible physical impairment; and alternative treatment is sought from outside the health system, often with economic and social consequences for patients and their households. In-depth understanding of the role and treatments provided by community level providers, both formal (community health assistants [CHAs], community health volunteers [CHVs]) and informal (faith healers, traditional healers) are often lacking. In this project, we seek to understand the experiences of CHAs, CHVs, faith healers and traditional healers in providing care for persons affected by SSSDs through photovoice.



This booklet is one of a series of four, with one booklet created for each group of participants, incorporating findings across two counties in Liberia (Lofa and Grand Gedeh) and presents the findings of the photovoice activity to identify core issues and themes. These photos will be presented in stakeholder meetings to inform the co-design and implementation of interventions to strengthen the provision of services for people affected by SSSDs at community level. We aim to show the unique role played by these community level providers in supporting people affected by SSSDs and identifying opportunities for earlier identification and initiation of treatment, along with options for the provision of more holistic care of people affected. From this point onwards we will refer to NTDs/ SSSDs as skin diseases.



MINISTRY OF HEALTH
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effect:hope
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This project is led by REDRESS, a collaboration between the Liberia Ministry of Health, the Liverpool School of Tropical Medicine (LSTM), the University of Liberia-Pacific Institute for Research and Evaluation (UL-PIRE), Actions Transforming Lives (ACTS), Effect Hope, American Leprosy Mission- AIM Initiative, Queen Margaret University, and is funded by the National Institute for Health Research (NIHR).



Photovoice Methods *and* Consent

Photovoice is a creative participatory method, which aims to empower participants to take ownership and be the storytellers of their own narratives.

Over the course of three weeks, these four groups of participants took photographs within their communities to capture their lived experiences in relation to their work, their interactions with their community and the health system, with a particular focus on skin diseases.

The process involved training of photovoice participants on the use of cameras and ethics of photography. Co-researchers were recruited as part of the core research team, which included people affected by and/or providing care for people affected by skin diseases who then supported and trained other people affected within their communities as photovoice participants to take photographs and articulate their meanings. The study took place in Lofa and Grand Gedeh Counties, within Liberia. These counties were selected to provide comparison between counties where integrated case management of NTDs has been introduced (Lofa County) and not yet introduced (Grand Gedeh County).



Glossary

Big Bag	<i>Liberian jargon to refer to Hydrocele</i>
Big Belleh	<i>Liberian jargon to refer to a pregnant woman</i>
Big Foot	<i>Liberian jargon to refer to Lymphedema</i>
Black Baggers	<i>Informal service providers who sell medication and treat sick people within the communities</i>
Community Health Assistants (CHAs)	<i>Health workers not employed by the formal health system. They work outside of a 5km radius to health facilities and are trained frequently to treat common illnesses at community level</i>
Community Health Services Supervisor (CHSS)	<i>Has undertaken a 3-month period of training and supervises CHAs/CHVs at community level</i>
Community Health Volunteers (CHVs)	<i>Work within communities that are located within a 5km radius to health facilities to support the delivery of health services on an adhoc basis</i>
Everlasting Sore	<i>Liberian jargon to refer to Buruli Ulcer</i>
general Community Health Volunteers (gCHVs)	<i>Some CHAs were formerly referred to as gCHVs</i>
Grand Gedeh County	<i>One of Liberia's 15 counties located in the South-East and the second largest county. One of 10 counties that is not implementing MoH integrated case management plan</i>

Lofa County	<i>One of Liberia's 15 counties located in the North and the fourth largest county. One of the five counties implementing case management plans</i>
Mid Upper Arm Circumference (MUAC)	<i>Measurement to detect acute malnutrition</i>
Neglected Tropical Diseases (NTDs)	<i>Disabling or debilitating diseases that usually affect poorer populations in tropical and sub-tropical countries</i>
Open Mole	<i>Refers to migraine headache and is often used to describe mental distress</i>
Papay	<i>An older male</i>
Severe Stigmatising Skin Diseases (SSSDs)	<i>Diseases that affect the skin and are associated with negative attitudes or discrimination</i>
Tablet People	<i>Also referred to as black baggers</i>
University of Liberia-Pacific Institute for Research and Evaluation Africa Center (UL-PIRE)	<i>A research center and one of REDRESS' collaborating partners</i>
Zoe	<i>Traditional spiritual personnel believed to possess supernatural powers to curse people and heal diseases</i>





Behind *the* Lens



"I am **Anthony Korvilay**, CHA from Kolahun district, Lofa County. I was a CHV from 2010 to 2017, and that is how I became CHA. Before becoming CHA, I was trained for four months on three conditions which are diarrhoea, malaria and pneumonia. They send me in the community to work, supplied me with drugs, and also supervision was allocated for me through my supervisors... The total population of my community is about eight hundred plus, both children and adults, I work with them smoothly up to present....I enjoy the job, because I am working for my community. During the time there was no CHA in the various communities, there were lot of deaths... taking place; maternal death, children under five dying, neonatal death were taking place. But today I can say thank God things are working fine with us, identifying children with pneumonia, the added treatment we are doing for them is making them well, and also making referral for adult. So, I have the ambition to do this work for my community."

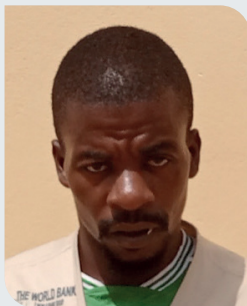
"My name is **Moses Wulue**. I am a CHA from Beazon, Cavalla, Grand Gedeh County. I treat children under five years old and refer the big people [adults] or pregnant women. I also do health talk in my community. I am motivated and feel good about my job role because of the community interaction. I am recognised and respected as a CHA by the community people. This can make me feel good about my job and it can also encourage me to do more for my community with all the challenges. However, I get disappointed at times, because of the long distances I can cover and the delayed incentives."





*"My name is **Vasco Zohn**, I am from Old Pohan...Cavalla District, Grand Gedeh County. I started CHA work in 2019 January. Before getting in the whole CHA business, I was a member of the Community Health Committee... I did it from 2015 to 2016, Ebola time. As a CHA, I serve as a bridge between the community and the health facility. This means that any information in my community, I am the one who can carry it. If I see any sickness that I don't know about, I can carry the report."*

*"I am **Edward S. Kendima**, I am a CHA from Foya, Lofa County... My job role is that I do treatment for children under five, I also do referral for adult, I am also a farmer... What motivates me to do this job is because...the people recognise me, and I gave thanks to the donor because of the training they have been giving me with some materials. So, I am very much happy about that... I have been in the field since 2008... doing voluntary job and I am very much happy to continue with my work."*



*"My name is **Regan B. Tokamawon** and I am a CHA from Bawaydee, Cavalla District. I started this Job since 2013...when I was gCHV. In 2017 we did training, and I became CHA. I am responsible to treat children from 2-5 years that get sick with malaria, pneumonia and diarrhoea. If they don't recover, then I can refer them to the clinic. I can also refer big belleh [pregnant women] and adults. I like my work because I'm helping the sick people."*

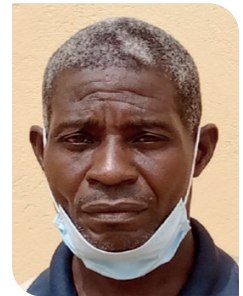


*"I am **Victoria Saah**, CHA, from Foya Pauloma clinic, Lofa County. I have been working since 2010 I was selected as gCHV. I work in my community, I do routine visit, I do care for children under five, then I also refer adults to the facility, I refer pregnant women, and I refer the children for their vaccine."*



*"I am **Cecelia S. Fomba**. I am a CHA from Kolahun district, Lofa County. I have been working since 2017 after we were trained. Before becoming a CHA, I worked as a CHV in 2016. I am... responsible for... children in my community, and I am helping the community people...on how to clean up our community and also...children that are getting sick from malaria, pneumonia and running stomach. ...I am really happy...doing this work in my community, ...because my community was not part of this CHA work...Today I am helping our community. The community people trust me and myself I trust them and we working hand in hand. So that any information from the facility you can get it from me and any information from the community the facility people can get it from me. So, I want to be thankful that I am doing job that will satisfy my people even though nothing you can do that is perfect to people but I thank God... they can understand me, and I understand them."*

*"Alright, I am **James Gaye** CHA, I work in Barway's town, Tchien district, Grand Gedeh County...In 2017, I went on training and the same 2017 December, we graduated from the training. When the training ended, we went back to our catchment area, what we learned is to treat children... So, my role I play in the community, I treat from 2 to 5 years... and if at all a trigger is found like measles, I have to do referral."*





Responsibility

CHAs are committed and take charge of their duties because it provides a sense of purpose for their work. Despite the challenges, they are happy and work tirelessly to ensure their communities have access to basic care and treatment. They are engaged in treating and referring patients, record keeping, conducting awareness, surveillance and routine visits from house to house. CHAs also appreciated supervision visits to improve the care they provide.



"In this photo I am happy for my supervisor to visit me, to correct me. Any mistake he will let me know so the next visit I can't make that mistake again. So, I am very happy."

"This is joint meeting we went to do health talk in one of the communities and how... they can take care of the net. How to [repair the] hole [in] the net good. So, we went to give that health talk, me and my colleagues."

Victoria Saah, CHA, Lofa County



"As you can see [in] this photo, it is all about our job responsibility as CHA on the field. When I went on the field, and I got this child and as you can see the work here, I am doing the MUAC for the child (mid upper arm circumference measurement to detect acute malnutrition). You know sometimes when we go the field, people don't allow us to treat the children, except they see the child is seriously sick, that's the time they can bring their children; but when I went on the field and I saw the child, the child was healthy in the first week I went there. But the second routine visit I saw the child body draining down; so, I decided to do the child MUAC to know whether the child is... malnourished or is a healthy child."

"As you can see, after treating the child, I am doing the recording on the routine visit form."

Moses Wulue, CHA, Grand Gedeh County





"Okay, this picture represents the work that we can do in our facility. So, these [are] our CHAs they [are] sitting in their meeting to discuss something related to health. So, this is a meeting between ourselves, the CHAs. It is [part of the] CHA role. Yes, because it is health education."

Edward S. Kendima, CHA, Lofa County



"This boy has a health problem with sore all over in his hair...I came across this condition while we were keeping surveillance. And when you are keeping surveillance, you do not only look for what you are told to but to include any other problem that you think is a health issue. I came across this problem in my community."

Anthony Korvilay, CHA, Lofa County

"Yes, this is...CHA doing her treatment and when she finished doing her treatment she is recording her message in her book."

Victoria Saah, CHA, Lofa County





Access to Care

Access to quality health care services is important for promoting and maintaining health, in referral, preventing and managing disease, reducing unnecessary disability and premature death, and achieving health equity for all.

This theme focuses on physical access, transportation and the role of the CHAs in referring people affected to support access to care. However, CHAs underscored lots of difficulties which people affected by skin diseases encounter when accessing care at health facilities. Some challenges include, hard-to-reach terrains, absent or only a single ambulance to cover many facilities, and underdeveloped bridges which are inaccessible during the rainy seasons. Due to numerous challenges, people affected with skin diseases resolve to access services from informal service providers such as black baggers, faith healers or traditional healers.



"Change is taking place in the community. We used to take hammock on our heads, carrying patients to the facility... Today we are thankful... that we... have ambulance that can come and pick up patient to get to the various facilities."

**Anthony Korvilay, CHA,
Lofa County**



"Here is a view of a monkey bridge that is going to the other community... This photo represents a health problem also, because ... whenever we get into the rainy season people get to use this way to get to the facility but when the water gets full at the end of day people are not able to cross to get to the facility... this monkey bridge is not well prepared. Sometimes, you are walking in it, it can be shaking. Sometimes, how the ropes locking are not really guaranteed... So, I took this photo to let you know that my very self.. walk on this monkey bridge to get to the community."

Anthony Korvilay, CHA, Lofa County

"This particular man, ...his hand is big and the top part burst... He used to go to the hospital and then the tablet people (black baggers) are the ones who been treating him. Yes, they (black baggers) are the ones treating people in the community, and they can't go to hospital."

Vasco Zohn, CHA, Grand Gedeh County





"This lady, her husband has everlasting sore [buruli ulcer - skin disease]. We don't treat people with these kind of cases, we only refer. But the tablet man (Black bagger) can always come to the house and the old lady buy medicine to treat her husband sore".

Moses Wulue, CHA, Grand Gedeh County



"This is the photo of my EPI (Expanded Program for Immunisation) staff... giving injection to the pregnant woman."

Victoria Saah, CHA, Lofa County



Community Acts *for* Change

The CHAs highlighted the importance of community participation in making decisions pertaining to their health and wellbeing. With support from the Community Health Committee and other community structures, community members are motivated to ensure environmental cleanliness which is paramount to their health. Health workers also develop maps to indicate the various locations of health facilities and towns which is useful during case detection and planning of health activities.



"This my photo, community people are together discussing about the community. To me it is a community work the people are doing because they are in community meeting. They were discussing about the hand pump that spoiled."

"This photo, the man is drawing the community map. Yes, the man was drawing the community map to put it up so that any visitor see they will know exactly that this road in this town."

Cecelia S. Fomba, CHA, Lofa County



"In this photo, you see women are weeding grass from around the pump... when you look on this picture, you will see the bad side and the good side. The good one that [is] there, they [are] doing the cleaning around the pump... The second one, the pump is not finished. So, before taking this photo, this morning I passed there, [I said] 'why you didn't tell your men to fence the pump?' ... The photo, it shows that some people in the community they are doing their work but we the CHAs, sometimes what we are talking about they can't go by it [not do the action we advise]. Weeding grass around the pump is good, but the fence is not there."

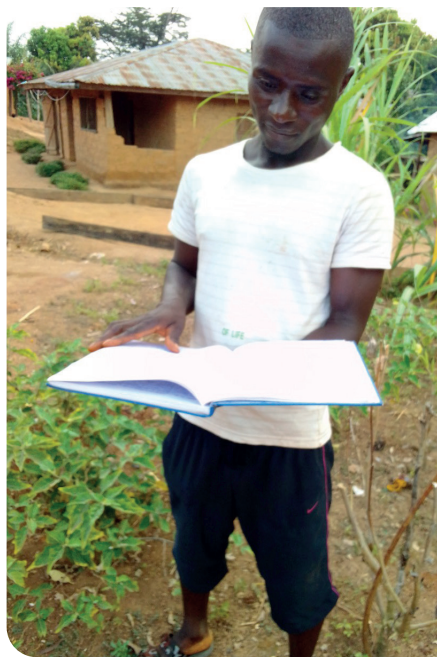
**Vasco Zohn, CHA,
Grand Gedeh County**





"Here is a view of this community. The community is very clean. And this community was declared open defecation free. So, this community I call this photo a good health".

Anthony Korvilay, CHA, Lofa County



"CHC [Community Health Committee] secretary is going around to see whether the community is clean. When he goes anywhere [that] the place [is] dirty he tell the people to clean it. Those that will refuse he write their names and carry it to the Town Chief. The man gets the book because when he reaches your area and the area is bushy he writes your name and fines you".

Cecelia S. Fomba, CHA, Lofa County



Links between Environment *and* Ill Health

A number of specific environmental issues can impede human health and wellness. These include lack of access to health care, poor infrastructure and poor water quality. CHAs identified some unsafe water sources that are simultaneously used for drinking and defecation which is harmful to their health. They also have access to hand pumps which are untidy, but are considered safe.

“This photo also talks about a [needed] change in the community. It means, these people also they don’t have drinking water and again they don’t have toilet. So, they use the water to do both thing. While others are toileting in it, others are taking it for drinking. I took this photo; I talk to them that this is not good. When you are doing this, you are harming yourself.”

**Edward S. Kendima,
CHA, Lofa County**



"I think you [are] seeing this is a bathroom and right side the bathroom they have the dump site...I felt bad because is not good. This picture in my community is not good."

James Gaye, CHA, Grand Gedeh County





"Here is the photo that represents this community. It is a hand pump. People drink from the hand pump and get safe drinking water from there. So, I call this photo a good health practice in the community. So far so good. Good health practice in the community."

Anthony Korvilay, CHA, Lofa County



Pride *in their* Work

CHAs emphasised several sources of motivation in their work, which drive them towards achieving their goals. They highlighted the use of bikes as transportation to get to the communities during outreach.

CHAs also described being inspired by their jacket as a means of recognition, the availability of drugs and materials, and community interaction as providing motivation. These factors certainly influence and improve their efficiency to serve their communities including those people who are affected by skin diseases.

“When you [are] ready for your routine house visit, when you meet your people, you speak to them correctly, through your communication the way you will act, when they have any patient there, they will tell you say ‘oh I have this patient’. But when you go visit someone don’t act like you are health worker and you are proud. So, when I reach in the community we share fun, I share fun with the people; and then I ask them for the children, how the children coming on.”

Vasco Zohn, CHA, Grand Gedeh County



“Yes, the routine visits in the community, you have to go from house to house to know the problem each of them has; whether somebody there sick for referral or like these people we just passed by. People get this sickness, and they are in the house. If you don’t go and visit, you will not discover whether they get this sickness.”

**Moses Wulue, CHA,
Grand Gedeh County**



"Yes, this photo it means that I am so happy about the work under REDRESS. Some of the thing that can make me happy is when I am working".

**Cecelia S. Fomba, CHA,
Lofa County**



"This is a CHA picture when they were going for the routine visit. After taking the training he went and explained the whole thing to them. So, they were ready now to go and start the work. So, he was in the mood of going to start the work."

Edward S. Kendima, CHA, Lofa County

"Here is the photo, the CHA is in the photo, sitting on the motor bike to go and visit the other community to talk to them on the health issue. So, the photo is representing motivational photo. Because it motivates me highly to do my work. During that time, I was walking but now I have motorbike, I am able to use to go and do my work smoothly."

Anthony Korvilay, CHA, Lofa County





Stigma

CHAs highlighted the impact of skin diseases on the affected persons. They may experience disability or deformities which can affect their social interaction within their community and society. Some people affected by skin diseases also experience mockery, discrimination, and social exclusion. Due to common belief that skin diseases have a supernatural cause, people affected are often reliant on the informal services like faith healers, traditional healers and black baggers.



"The sore was caused by a snake bite; she was bitten by a snake. African herb was applied but it did not help her. Because of that, her foot has gotten rotten, and she has even gotten crippled. So, they have decided to bring her for treatment, and she is undergoing it, but the sore has not gotten well yet. The health problem is that this woman, due to her condition, is unable to do anything for herself. Even to get water or food to eat, other people have to help her to get those things, so she is very embarrassed with this sore."

Anthony Korvilay, CHA, Lofa County

"Yes, this photo is an everlasting sore (skin disease).

This photo, I can refer to this photo as NTD. Yes.

The gamble seeds that you see on the foot of this woman are used by the people as a sacrifice.

In our settings, according to them, when such a thing happens, it is linked to witchcraft activities.

So, they put the gamble seeds, according to their tradition, so if it is satanic, it should go away. So that is the reason why they used the gamble seeds."

Anthony Korvilay, CHA, Lofa County





"This person all his two feet, everything big-big, he's just sitting down to the house, and he can't get outside. He just inside and the people feeding him inside the room because no way for him to walk."

Vasco Zohn, CHA, Grand Gedeh County

"This man is a leprosy (skin disease) patient. So, each time I go for visit to him, he doesn't come out because he doesn't want people to mock him. Each time I go to his house, I go there, I will give him all the health talks and I refer him to go to the health facility, he doesn't go. I even called his little brother and I explain it to him, he said 'Give me the referral slip, I will carry the man to the hospital'. I took the referral slip and I gave it to him, [but] his brother never carried him."

Moses Wulue, CHA, Grand Gedeh County





"Alright, this is a [patient with] leprosy. So, this sickness here, is very bad in the community. When somebody have this sickness, you can't see the person wearing short trousers in the community. That's the time he will wear long sleeves, long trousers. Everyday shoes can't move from his foot because he [is] not wanting people to look fearful when they see this type of sickness here on him, so he [is] hiding it. So, this sickness is all over the man's body... he say because when he show it to the community people, people will be teasing... him and be showing finger at him that he get bad sickness on him.... So, that's the reason he [is] hiding himself."

Regan B. Tokamawon , CHA, Grand Gedeh County



"Yes, this photo is a woman, she has an everlasting sore (skin disease), and this sore has spent more than three years and it can't get better. She can always have bandage on her foot because she does not want to show it out for people to see it; or even when she loose it, fly can't give her chance. So, that's about three years sore there."

Vasco Zohn, CHA, Grand Gedeh County



Recommendations of Actions for Change *from CHAs*

CHAs placed emphasis on the importance of their role in raising awareness about, identifying and referring people with skin diseases to the health facility. They highlighted the importance of confidentiality and of building relationship with people with skin diseases. CHAs also emphasised the value of ongoing training and supervision to improve their knowledge and skills, along with pictorial materials to help raise awareness within their communities and the importance of financial support for their work. CHAs also highlighted the need for rain gear to help them as they do their work.

“Yes, to care for them, firstly don't be afraid of them; because some of them when their hands [are] rotten, people can be afraid of them. So, as a Doctor when you reach there, go around them, then you will hear what [is] in their heart. But when you say 'I will not go near them because their hand is smelling'; tomorrow when they see you, they will not talk to you.”

Grand Gedeh CHA Group Discussion

“The idea I have concerning these diseases, is how to convince the person ... at least if you talk to them, you encourage the person, you talk the good side and the bad side of that disease, so you be able to convince the person, so you can be able to work for the person. But if you can't convince the person, then you will not be able to work.”

“What can help me is [to] continue training [me]. Because if I am trained [on] how to identify these things, How to find them then I will know how to identify them. ...And also materials...if you are talking to these people you need to have some materials, picture examples that you will show to the person, that this is the work that we can do and you talk to them and show them the pictures so that person will feel that what you are saying is true. You have to get that working materials with you... Even [trained] by the government. You know if the government take you to do this kind of work, they train you then you will be supported.”

“One that will help me is the awareness, because the awareness will not only be done in the community, it can also be done on radio, inform, go on the media inform other people because not all community has CHA, and not all community CHA will be able to get to that particular community, but when they are inform on air, everybody playing radio, people will listen to it.”

Lofa CHA Group Discussion



Reflections on the Photovoice Process *from CHAs*

CHAs reflected on some of the challenges relating to the photovoice process, particularly when asking permission to take a photo of someone affected by a skin disease, because of the stigma which some people experience and their reluctance to be photographed as a result. Other CHAs reflected on the positive aspects of the process, commenting on the hard work they do to serve their communities and the positive actions happening as a result.



“After we finished with the training, the first training, when we go back on the field, some community when you [are] there and see somebody is not feeling alright like that like big foot like that, when you tell the person ‘oh I want to take your photo’, they can refuse. Because the reason is that they say when you take their photo then you go start showing it around and people start pointing finger at them in the community. So, they don’t want for nobody to take their photo. Even some of them in the community they are hiding themselves. When you are going around and you call for awareness like that, they don’t even want come. Even sometimes when you go around and you see somebody that is not feeling alright like big foot, they can refuse to take because they say, you are taking their photo to go and laugh at them. So, these are some problems we can face on the field.”

Grand Gedeh CHA Group Discussion

“I did my community entry. That is [I] put them together I explained what I am coming to do and the people agreed and my role as a CHA I explained all those ones to them. Then, I told them about sicknesses that people are hiding and also can be ashamed of. The sicknesses are not there to hide with it and the people agreed what I explained to them, they agreed. And also enjoyed taking the pictures too. Because this picture it shows certain example to us that we the CHAs our role in the community. The community work is very hard. Some things that are there the community people are not supposed to do it and we the CHAs we advise them to do it on the good side.”

Lofa CHA Group Discussion

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For further information please see:



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