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USAID's Act to End Neglected Tropical Diseases | West  
Gender Study Phase Two:  
Qualitative Gender Analysis and Gender Strategy  
March 2020



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## LIST OF ACRONYMS

ADS	Automated directives system
CDD	Community drug distributor
CHW	Community health worker
CPHS	Community-Based Health Planning and Services
DALY	Disability-adjusted life year
DOT	Directly observed therapy
FGS	Female genital schistosomiasis
GESI	Gender equity and social inclusion
GBV	Gender-based violence
LF	Lymphatic filariasis
MDA	Mass drug administration
MEL	Monitoring, evaluation, and learning
NTD	Neglected tropical disease
NTDP	Neglected tropical disease program
PC	Preventative chemotherapy
SBC	Social and behavior change
SCH	Schistosomiasis
STH	Soil-transmitted helminths
STI	Sexually transmitted infection
TT	Trachomatous trichiasis
USAID	United States Agency for International Development
WHO	World Health Organization

## INTRODUCTION

Act to End Neglected Tropical Diseases (NTDs) West is a five-year (2018–2023), \$200 million program funded by the U.S. Agency for International Development (USAID) to control or eliminate five NTDs in sub-Saharan West Africa.<sup>1</sup> The FHI 360-led consortium includes partners: Helen Keller International (HKI), Health Development International (HDI), Deloitte Consulting, World Vision, AmeriCares, and AIM Initiative.

Act to End NTDs | West expands and deepens USAID’s efforts to control or eliminate trachoma, lymphatic filariasis (LF), onchocerciasis, schistosomiasis (SCH) and soil-transmitted helminthiasis (STH) in 11 West African countries—Benin, Burkina Faso, Cameroon, Côte d’Ivoire, Ghana, Guinea, Mali, Niger, Senegal, Sierra Leone, and Togo. The new program supports disease-endemic countries to eliminate and/or control NTDs using preventive chemotherapy (PC), a proven, cost-effective public health intervention.

Act to End NTDs | West will build on the achievements of END in Africa and ENVISION in West Africa in their efforts to eliminate LF and trachoma as public health problems and eliminate onchocerciasis in selected countries. It aims to make NTD programs capable of sustaining treatment for long-term control of SCH, STH, and onchocerciasis (the latter in selected countries) and to mainstream NTD programs into the national health system.

As a way to ensure Act to End NTDs | West is equitably addressing the needs of men, women, boys, and girls with NTD control and elimination activities, as well as comply with USAID’s Gender Equality and Female Empowerment Strategy, the program team engaged two FHI 360 gender advisors to conduct a gender analysis and create a gender strategy.

## PROGRAM-WIDE ACT | WEST GENDER EQUALITY AND SOCIAL INCLUSION (GESI) STRATEGY

Based on the findings from the desk review on gender and NTDs, quantitative workbook data, and the qualitative field study, we have developed a comprehensive gender and social inclusion strategy for the Act | West program.

### Goal

The goal of the gender strategy will be to formalize an actionable set of recommendations, based on literature and quantitative and qualitative data, that will contribute to overall achievement of program objectives as well as increased gender equality throughout implementation of the Act West program.

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<sup>1</sup> The diseases slated for elimination are: trachoma, lymphatic filariasis (in all endemic USAID-supported countries) and onchocerciasis (in selected countries according to USAID priorities). The diseases slated for control are: schistosomiasis, soil transmitted helminths (in all endemic USAID-supported countries) and onchocerciasis (in selected countries according to USAID priorities).

## Objectives

- Everyone, regardless of sex, disability status, ethnicity, religion, language, national or social origin, and economic status will have equal and improved access to treatment for onchocerciasis, LF, STH, SCH, and trachoma as relevant, through the 11 Act West program countries
- Increase knowledge of diseases and reasons for MDA access to information on MDA timing and locations, and education on potential side-effects to make an informed decision to participate in MDAs
- Promote and support gender equitable participation as CDDs, removing barriers for women to safely and inclusively participate as CDDs in NTD programs

## RECOMMENDATIONS FOR PROGRAM IMPROVEMENTS

**Recommendation #1: Increase the number of female CDDs, and where culturally appropriate and after consultation with the lowest level administrative unit context, pair male and female CDDs, if possible.**

### Rationale

Ensuring inclusive growth in the sector – by allowing both women and men to share their skills and benefit from opportunities – is central to achieving development outcomes that do not exacerbate existing labor and income disparities, but rather builds on, serves and enhances the unique capacities and priorities of women and men alike.

These findings are supported by the literature from other countries implementing MDA (see desk review in Appendix 3). From Dean et al.'s study, they found supporting evidence that gender of CDDs informed interactions and compliance with community and household members, predominantly women. They also highlighted the risk this posed to accurately collect census data to inform program supplies and coverage. "Due to the recording process CDDs undertake, it is possible that if they don't enter the household, members of the household could become 'missing' within data sets recorded in the CDD register."<sup>2</sup>

Participation of female CDDs can improve the success of MDAs: more people will be reached with the drugs, and more people will understand the nature of the diseases and the importance of taking the drugs. This increased responsibility can lead to greater recognition and support both career and social advancement, which is particularly helpful for female CDDs<sup>3</sup>. From a couple of other studies, female

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<sup>2</sup> Dean, L. et al. Neglected Tropical Diseases as a Litmus Test for Universal Health Coverage? Understanding Who is Left Behind and Why in Mass Drug Administration: Lessons from Four Country Contexts. 2019. Accessed 1/05/2020: <https://doi.org/10.1371/journal.pntd.0007847>

<sup>3</sup> Theobald S, MacPherson EE, Dean L, et al. 20 years of gender mainstreaming in health: lessons and reflections for the neglected tropical diseases community. *BMJ Glob Health* 2017;2:e000512.

health volunteers reported taking on this role as empowering to women, and leading to increased mobility, knowledge<sup>4</sup>, feelings of accomplishment, and respect from husbands and family members.<sup>5</sup>

### Recommended Activities

- Conduct sensitizations on gender dynamics, GBV, sexual harassment, and value of communities supporting more women serving as CDDs (including allowing for more flexibility around literacy requirements) with NTD program officials from the MOH and districts (which they will be expected to flow down to MDA supervisors, and CDDs through district-level officials during formal trainings of CDDs).
- Through sensitizations during recruitment calls for new CDDs, highlight the benefits of women serving as CDDs to both the community and the family, including ability to reach women more effectively in conservative communities. Encourage officials/leaders to nominate more women for these roles, given their interest and aptitude for the work and the opportunity it provides to serve in additional community health-related roles. This should include increasing flexibility regarding literacy in the selection criteria to become a CDD (particularly if CDDs work in pairs where one CDD is literate), and add “soft” skills such as good communication, patience, etc. Emphasize that the role of CDD is voluntary and a woman should not be pressured to apply if she is not interested.
- Advocate for incentives on par with each countries’ practices related to CHW incentives to make it easier for women to engage in CDD work, and in general improve CDD retention and motivation. In the three countries we conducted the study in, both the Ministry officials we spoke to, and the CDDs themselves confirmed that Community Health Workers (often the same people) doing other types of health outreach and community work, were being given higher stipends for those activities than for the MDAs. This creates resentment and discouragement given that the MDA work is often more intensive, being door to door, than their other campaign work. So other health programs within the same countries are providing higher incentives making MDA work less appealing to potential CDDs. While the lack of incentives for most CDDs was cited as a challenge for both men and women, it appeared to be a much greater barrier for women. To volunteer as CDDs, women have to balance their household duties with the burden of this additional work. This recommendation was also included in the recently released Discussion Paper on the Gender Dimensions of NTDs, led by UNDP: *“Women from rural low income areas, in particular, already have considerable daily tasks to ensure survival and sustenance and undertaking additional roles can risk further lost economic opportunities. When implementing NTD programmes, these factors should be considered so that health systems, donors and implementing partners provide adequate remuneration and support to women and other CDDs so that inequalities in gender and income are not further exacerbated.”*<sup>6</sup>
- Transportation is also more difficult for many women due to social norms and lack of access to bicycles and motor bikes. Many CDDs suggested providing rain boots and hats or rain jackets as incentives, which would also be a motivation for male CDDs. (In fact, the provision of raingear

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<sup>4</sup> Campbell SJ, Nery SV, McCarthy JS, Gray DJ, Soares Magalhães RJ, Clements ACA: A Critical Appraisal of Control Strategies for Soil-Transmitted Helminths. Trends in Parasitology 2016, 32:97–107

<sup>5</sup> Krentel A, Fischer PU, Weil GJ: A Review of Factors That Influence Individual Compliance with Mass Drug Administration for Elimination of Lymphatic Filariasis. PLOS Neglected Tropical Diseases 2013, 7:e2447.

<sup>6</sup> UNDP. Discussion Paper on the Gender Dimensions of NTDs. November 2019.

[http://adphealth.org/upload/resource/2523\\_AD\\_P\\_Discussion\\_Paper\\_NTDs\\_211119\\_web.pdf](http://adphealth.org/upload/resource/2523_AD_P_Discussion_Paper_NTDs_211119_web.pdf)

might help to achieve higher coverage rates in some cases, given that MDA can continue during rainy periods). It is not necessary to provide transportation reimbursement to all CDDs but only to those who have to travel quite far or have to pay transportation costs out of their own pockets.

- Increase flexibility regarding literacy in the selection criteria to become a CDD, as long as the CDDs are able to accurately fill in the registers, and add “soft” skills such as good communication, patience, etc.
  - In Côte d’Ivoire, the most important criterion for selection as a CDD is literacy. Candidates are required to take a literacy test at the district health office. In Ghana and Sierra Leone, literacy is an important criterion, but it is not rigorously enforced. It is clear that there are many other important skills needed to become an effective CDD (e.g., good communication skills, patience, diligence, ethic of hard work, and honesty). Many people reported that female CDDs have these skills in greater abundance than males. If more women join the ranks of CDDs, it is more likely that CDDs could work in male–female pairs. If the female CDD paired to work with a male CDD is not literate, she can nevertheless contribute other skills during the drug administration. The literacy criterion could be removed if at least one member in a pair is literate and can ensure the registers are filled out correctly.
  - Amend the training curriculum for CDDs to include a range of additional social skills, including communication, patience, ethics, and honesty, as well as sexual harassment and GBV topics.

**Recommendation #2: Improve synchronization of MDAs near international border districts in countries where performance is particularly challenging in border districts.**

Rationale

MDAs in districts that border neighboring countries tend to miss community members who travel between countries. These community members are at risk of missing drug distributions in both countries. These missed individuals include both men and women (with men traveling alone more for commerce/work, and women and families traveling for life events such as funerals, weddings, etc. or entire families in the case of nomadic communities). However, the qualitative study and workbook data showed that MDA coverage is lower for males than females in border districts.

Recommended Activities

In border districts, include border check-point officials in the CDD trainings. Both during and for few weeks following an MDA, have the border officials distribute drugs at the checkpoints as people cross the border. This would be helpful given the immense challenge of streamlined timing and coordination of MDAs between countries due to different donors, project timelines, etc.

**Recommendation #3: Improve guidance to community health workers and CDDs on how MDAs can better reach marginalized individuals, including people with disabilities.**

Rationale

While the qualitative data shows little evidence of people with disabilities being systematically missed by MDAs, some challenges were cited. Findings from this study showed the importance of engaging with people with disabilities in MDA strategies, as some people felt that door to door was the best method for reaching people with disabilities while others preferred to be reached with MDA at the places they



congregated to beg<sup>7</sup>. Additionally, our desk review found, for example, that people who are unable to stand due to a disability may not be measured properly (using a dose pole) for the appropriate drug dose. CDDs use different strategies in these circumstances, but these should be standardized to ensure they are applied uniformly and accurately, and that CDDs demonstrate sensitivity. There also appears to be little or no engagement with leaders and stakeholders working with people with disabilities. A few CDDs in Sierra Leone, for example, mentioned that it was hard to work with leadership structures within urban communities consisting of people with disabilities. It was also sometimes hard to convince people with disabilities to take the drugs. This was especially true of individuals with lymphedema, hydrocele, or oncho-related blindness. Many times, these individuals refused to take the drugs because they thought it was “too late for them” to benefit. CDDs can receive better training on how to explain the benefits of the drugs to those with disabilities caused by one of the targeted diseases.

Marginalized ethnic groups, such as the Fulani in some areas, have been difficult to reach during MDAs. Challenges include their nomadic lifestyle, mistrust between them and local populations, and strong patriarchal social norms that do not allow women to be engaged by male CDDs of a different ethnic group.

#### Recommended Activities

- During training of MDA supervisors and CDDs before and during the MDAs, discuss working with people with disabilities and provide specific guidance on how to better serve people with disabilities. Include standardized training on measuring individuals who are unable to stand (such as those using wheelchairs) in order to ensure proper ivermectin dosage.
- Include leaders of people with disabilities in urban communities in outreach on MDAs.
- Continue to engage with leaders of Fulani and other marginalized ethnic communities in order to sensitize them to the availability of the drugs and to discuss more effective ways CDDs can access family compounds to provide the drugs.

#### **Recommendation #4: Improve pairing of CDDs with communities of their own ethno-linguistic group to address social inclusion of marginalized ethnic groups.**

##### Rationale

The program already does a good job in most communities of assigning CDDs from the same ethno-linguistic group. However, this proved to be a greater challenge in urban areas where CDD catchment areas often include households from different ethnic and linguistic groups. Given the importance of maintaining trust between community members and CDDs, great care should be taken to prioritize assigning CDDs who share a common language or ethnicity with the targeted community. This is particularly important in areas or communities where there is historical mistrust—such as among Fulani communities and in Ghana where mistrust among rival political parties, often falling along tribal lines, was mentioned. This issue also came up in the literature through a study on MDA compliance in Sudan,

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<sup>7</sup> Dean, L. et al. Neglected Tropical Diseases as a Litmus Test for Universal Health Coverage? Understanding Who is Left Behind and Why in Mass Drug Administration: Lessons from Four Country Contexts. 2019. Accessed 1/05/2020: <https://doi.org/10.1371/journal.pntd.0007847>

where some nomadic communities refused treatment from Sudanese health workers of a different ethnicity because of distrust between the two ethnic groups.<sup>8</sup>

#### Recommended Activities

- For urban areas and other catchment areas that include multiple ethnic groups, include the CDDs' ethnicity in factoring which catchment areas to place them, which doesn't appear to always happen, or pairing CDDs with different ethnic or tribal affiliations within diverse catchment areas, to decrease language and cultural barriers between CDDs and the communities they serve. Additionally, we can provide CDDs working outside their home community with badges to increase their profile and trust.

#### **Recommendation #5: Improve messaging and information about NTDs and MDAs, especially to men, pregnant women, and CDDs.**

##### Rationale

Many community members across all three countries expressed a desire to have more information about the targeted NTDs, as well as potential side effects of the medications distributed. While both men and women wished for more information and visual aids, only men cited lack of communication as a reason for refusing to take the drugs.

#### Recommended Activities

- Provide CDDs with posters and other visual aids that are adapted for low literacy populations and show pictures of untreated NTDs in order to raise awareness about the diseases and how people contract them. We saw these in Cote d'Ivoire at health facilities, but it doesn't seem that CDDs are using them effectively during MDAs and really explaining them to people.
- Increase mass media messaging in urban areas or other areas with low coverage. Adjust timing or approaches to improve awareness and decrease refusal rates, particularly among men as many men reported never having heard this information.
- Supplement the current CDD training curriculum with modules that explain more about the NTDs themselves, modes of transmission, importance of taking the drugs, potential side effects of the drugs for children and adults, what the drug risks are to pregnant women, and how to dispel myths about the drugs.
- Pilot a cadre of mostly female volunteer "MDA Champions" to do SBC and outreach on NTDs and MDAs in areas where refusal rates are high and/or in disease hotspots. These volunteers would not engage in drug distributions, but rather could prime the communities for the MDAs a couple of days in advance to increase awareness, help alleviate concerns about side effects, dispel myths about NTDs and MDAs, and reduce stigma towards people with NTDs. They will be selected by the community leaders based on their communication and interpersonal skills, and their status as well-respected community members, and their desire to serve in this role and help their community. These Champions can also do specific outreach to pregnant and breastfeeding women to explain the side effects of the drugs for pregnant women, why it is important not to take the drugs while pregnant, and when and if women can take the drugs

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<sup>8</sup> Theobald S, MacPherson EE, Dean L, Jacobson J, Ducker C, Gyapong M, Hawkins K, Elphick-Pooley T, Mackenzie C, Kelly-Hope LA, et al: 20 years of gender mainstreaming in health: lessons and reflections for the neglected tropical diseases community. *BMJ Global Health* 2017, 2

while breastfeeding. These volunteers would attend the CDD trainings for their district to maximize efficiencies and would be provided visual aids about NTDs.

- Pilot increasing the time districts have to prepare for the MDAs. District health offices are given a couple of days to prepare for an MDA. They request at least two weeks, if not three to four weeks.

## QUALITATIVE FIELD RESEARCH IN SIERRA LEONE, COTE D'IVOIRE, AND GHANA

The gender analysis was broken into two phases. During Phase 1, a desk review on NTDs and gender was conducted using secondary sources and the summary of some limited quantitative data analysis from USAID-funded NTD programs from 2012–2017 in West Africa (see Appendix 3). Phase 2 included qualitative research in a subset of program implementation countries—Côte d'Ivoire, Sierra Leone, and Ghana—and development of a gender strategy for the program (based on the literature review and qualitative research).

Findings from the Phase 1 desk review showed that sex-disaggregated NTD programming data from implementation countries are limited, especially from the sub-national level, and include only approximate estimates on treatment coverage by sex and community drug distributor (CDD) trainings by sex. The literature presents various ways that females and males of different ages and from different marginalized groups might be disproportionately missed through mass drug administration (MDA), but the available quantitative program data do not provide a clear picture of the extent this is happening across program implementation sites. The desk review also provided quantitative data on CDD training disaggregated by sex from 2012–2017<sup>9</sup> but provided little information on how to engage more women as CDDs and how that might impact overall project performance.

Phase 2 of this gender analysis focused on filling in some of these data gaps—using qualitative research to understand the reasons behind any disparities in MDA coverage and identify ways to engage and empower women and other disadvantaged populations in decision making, program implementation, and problem solving. These insights will ensure the Act to End NTDs | West program is able to meet its objectives in an equitable and gender-sensitive way that improves the lives and health of communities across the 11 program countries.

### Goal

This analysis was designed to inform an NTD program gender strategy, which will be developed in collaboration with USAID, the NTD country programs, and the headquarter program management teams. The gender strategy will in turn inform the program's technical implementation approach throughout the life of program and will add to the knowledge base on gender and NTD programming in West Africa.

### Primary Objectives

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<sup>9</sup> The available data on CDDs are limited to CDD training participants and are therefore a proxy for active CDDs and not necessarily the exact number or make up of active CDDs.

To explore:

- how NTDs might differentially impact women and men—recognizing intersectionality of gender, age, location, disability, etc.
- how unequal gender norms, unequal power dynamics (including social exclusion of people with disabilities) might affect the attainment of program results
- how gender-focused program activities could advance gender equality and social inclusion

## Design

This gender analysis collected qualitative data through key informant interviews (KIIs) and focus group discussions (FGDs) in Côte d'Ivoire, Sierra Leone, and Ghana. For this purpose, it adapted the domains of gender analysis as outlined in USAID's *ADS Chapter 205: Integrating Gender Equality and Female Empowerment in USAID's Program Cycle*.<sup>10</sup> The domains applied were: policies and regulations; patterns of power and decision making; gender-related health and social impacts of NTDs; access to information about NTDs and MDAs and access to and compliance with MDAs; and cultural norms and beliefs impacting the roles of male and female CDDs.

## Population

Approximately 477 individuals participated in the study across the three countries. KIIs and FGDs of 6–8 individuals were conducted as follows:

- KIIs with in-country program staff from FHI 360 and HKI (program leadership; M&E; field managers, etc.) (1–2 per country)
- KIIs with national- and district-level Ministry of Health officials involved in NTD programming (3–5 per country)
- KIIs with members of international non-governmental organizations involved in NTD programming (1–2 per country)
- FGDs with community leaders (3 mixed sex groups per country)
- FGDs with single-sex groups of mothers, fathers, and grandmothers of school-aged children (3 of each for 9 groups total per country)
- FGDs with CDDs (6 groups per country: 3 all-female and 3 all-male groups)
- FGDs with health providers (facility-based nurses at the community level) involved in NTD programming (3 groups per country)

## Study Sites

The research study took place in the capital cities and one or more communities in three selected districts each in Côte d'Ivoire, Sierra Leone, and Ghana. The sites were chosen based on quantitative data on overall program coverage; sex-based differences in program coverage; representativeness across NTDs (including at least one district that had endemicity for each disease); presence of LF hotspots; religious ethnic group distribution; urban and rural dynamics; type of local economies; and border areas/migrant populations. In Côte d'Ivoire, the sites selected were Abidjan and communities in Korhogo, Divo, and Touba districts. In Ghana, the sites selected were Accra and communities in the

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<sup>10</sup> Available at: <https://www.usaid.gov/ads/policy/200/205>

following districts: Kpandai (Northern Region), Sekyere Afram Plains (Ashanti Region), and Ahanta West (Western Region). In Sierra Leone, the sites selected were Freetown and communities in Koinadugu, Kenema, and Western Area Rural districts. For additional info on program coverage and prevalence data, please refer to Appendix 2.

**Table 1: District profiles for study sites**

Regions	Districts	Primary economy	Migrant/nomadic populations	MDA performance	MDA types	MDA coverage rates	Failed pre-TAS
<b>Cote d'Ivoire</b>							
Kabadougou-Bafing-Folon	Touba	Agriculture, factory	No	93-98% for LF, OV, and STH	LF; OV; STH	Male > female for LF, OV, and STH	No
Lôh-Djiboua	Divo	Agriculture, factory, commerce	Yes	94%	LF; OV	Female > male	No
Poro-Tchologo-Bagoue	Korhogo	Mining, agriculture	Yes	83-99% for LF and OV	LF; OV	Female > male for LF and OV	No
<b>Sierra Leone</b>							
Northern	Koinadugu	Agriculture	Yes	~86% in 2018 for LF and OV; ~83% for STH in 2018	LF; OV; STH	Approximately equal in 2018	Twice
Eastern	Kenema	Gold mining, agriculture, commerce	Yes	~90% in 2018 for LF and OV; ~87% in 2018 for STH	LF; OV; STH	Approximately equal in 2018	Twice
South	WAR	Fishing, agriculture, commerce	Yes	85-87% for STH in 2018; 88-90% for LF in 2018	LF; STH	No data in 2017 but roughly equal in 2018	Once
<b>Ghana</b>							
Western	Ahanta West	Agriculture	No	82-94% for LF in 2018 and 68-74% for STH	LF hotspot; OV; SCH	SCH higher for males; LF and OV higher among females in 2018 but LF higher among males in 2017	Three
Northern	Kpandai	Agriculture	No	64%-69% in 2017 for OV	OV	OV higher for males in 2017	No
Ashanti	Sekyere Afram Plains	Agriculture	No	Poor for OV (43-52%); 56-72% for STH; 44-57% for SCH	OV; STH; SCH	OV higher for males in 2018; SCH and STH higher for males in 2017	No

## **Study Limitations**

While this qualitative gender analysis was intended to inform the overall program gender strategy, there are inherent challenges in extrapolating data from three countries to an additional eight program countries that may be quite different from Sierra Leone, Ghana, and Côte d'Ivoire. The study countries were selected based on a variety of factors including disease profile, social and religious makeup, MDA equity, and other health system considerations such as HIV prevalence and history of Ebola. However, we were limited in our data collection to program countries where safety and security were of less concern and where there was available in-country support and presence. A few known differences between some other countries in the program and the three in the study included: presence of active conflict; lower GDP/capita (Côte d'Ivoire and Ghana have much higher GDP/capita than most of the other countries in the portfolio); geography (all three study countries have access to the coast); and cultural differences specific to Sahel countries.

The available quantitative data did not always align well with the objectives of the GESI analysis, and MDA coverage data did not illuminate a broader pattern of coverage equality or inequality by sex. There are a few possible explanations for this, including data quality issues, especially in areas where drug ingestion appears to not have been directly observed by CDDs.

Another limitation was the lack of direct participation by any people with disabilities in any of the FGDs or KIIs. Our objective was to include 1–2 people with disabilities in each of the community FGDs, but this proved to be much more challenging than anticipated. The team reached out to Disabled Persons Organizations (DPOs) in each of the countries, conducted interviews with representatives from those DPOs, and asked questions about disability and inclusion in each FGD and KII. But supposedly no people with disabilities were ever “available” or met the inclusion criteria for participation in any of the communities—except one community in Côte d'Ivoire. We therefore had to base our findings of disability inclusion on the words of CDDs, health officials, and non-disabled community members.

## **FINDINGS**

Many of the findings were similar across the three countries as well as across the various cadres of respondents, although there were some key differences. Below presents the findings and recommendations for each individual field assessment country, followed by consolidated findings and overall program strategy.

### **Ghana Findings**

#### **Policies and regulations**

Ghana's Ministry of Gender, Children, and Social Protection is in charge of implementing the National Gender Policy, which outlines the broad priorities around gender equality throughout the various government sectors. However, implementation has been generally weak due to budgetary and capacity constraints within MoGCSP.

The Ghana Health Service's NTD office follows the World Health Organization (WHO) guidelines for MDA rollout and the selection of CDDs.<sup>11</sup> One government official in the NTD office of the Ghana Health Service (GHS) stated, "When it comes to gender issues, as a country, we don't have [gender] as a problem. The way the MDAs are done, whenever the CDDs are being chosen, it doesn't have anything to do with gender. It's who has the ability." This statement shows a relative lack of understanding of the gender dynamics in the selection of CDDs in Ghana.

### **Patterns of power and decision making**

Most people said that men are responsible for the upkeep and well-being of the family and that they wield more power in the family and community than do females, including decision-making around family healthcare.

Most women reported being able to make decisions about their own health care, including taking drugs through the MDAs. However, in Kpandai district (a conservative district in the north), men indicated that women need consent from their husbands to take the drugs. However, when women were asked if decision-making structures in the family impede them from ingesting the drugs without their husbands' permission, nearly all the mothers said they are able to take the medicine even if their husbands are not home. They said they even take their husbands' pills from the CDDs so that the men can ingest them when they come home later in the evening, indicating that CDDs in this district are not always directly observing treatment.

### **Differential impacts of NTDS on women and men**

The physiological impacts of the various NTDS can vary for men and women. With LF, women are more likely to experience lymphedema, but only men can get hydrocele. With respect to trachoma, women are more likely to experience trichiasis because of their proximity to children who are more often infected, according to key informants from the Ghana Health Service. Women can experience many unique complications from STH or SCH—impacting maternal and newborn health outcomes, HIV risk, and chronic anemia.

The findings in Ghana included mixed responses with regard to whether these NTD-related disabilities are more socially or economically harmful for women or men. In communities where people were better informed about the causes of these disabilities, reports of stigma were predictably lower (since people understood they could not "catch" disease from people with morbidities). However, that does not mean sufferers do not experience ostracization or other negative social effects. Most of the male community leaders in Kpandai district believed that LF is passed directly from person-to-person and that people contract the disease by being close to the infected person—which undoubtedly increases stigma towards people with LF-related disabilities.

Some male and female community members said that they knew men who had abandoned their wives because the wives had visible symptoms of lymphedema. However, none of the women who participated in the FGDs mentioned that they knew any woman who left her husband because he had a tropical disease. A few respondents stated that women with lymphedema would hide their disability by staying in the house (and over time become socially excluded) but that men they knew with hydrocele continued to be out in the community. Mothers and community leaders reported that some women

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<sup>11</sup> WHO guidance on selection of CDDs can be found here: <https://www.who.int/apoc/cdti/cdds/en/>

with lymphedema used to work in the markets as food sellers, but no one would buy food from them and they lost their livelihoods.

In addition to the potential negative consequences of her own NTD-related illness and disability, a woman carries an extra burden if a family member is disabled by an NTD. Across West Africa, it is the accepted role of women and girls to take care of ill or disabled family members.<sup>12</sup> Several women who participated in the FGDs admitted to having the burden of caring for a parent disabled by LF and the difficulties related to care giving.

The question “are women or men more affected by the diseases?” was interpreted in two ways by FGD participants. The first concerned the impact of the diseases. Most people—both men and women—concluded that women are more affected because they are the ones who take care of sick family members. The women themselves must work even if they are sick. If they are unable to work, it affects the entire family. Furthermore, a divorced woman with one of these diseases finds it very difficult to access funds for treatment. The second interpretation concerned the prevalence of the diseases among men and women. Responses varied from community to community and from group to group. People’s answers depended largely on who they knew with one of the diseases. (In reality, the different diseases affect different groups depending on their environments, the work that they do, their dependence on infected water sources, etc.)

#### **SBC messaging and access to information about NTDs and MDAs**

Across the board, both men and women said that women have more access to information about the drugs and the diseases than do men. Women have extensive networks with other women who share health information with each other. They are also more likely to hear the announcements made by health staff in the information centers, info-vans, after the sounding of the village gong, and in churches and mosques, according to female community members—even though the messages are meant for everyone. Men generally have less interaction with health staff and are away from their homes and communities more often than women, so they need to be reached through tailored approaches such as through radio or during evening times or early morning when they are more likely to be home. During the day they are mostly on their farms or at other places of work and lack access to concrete information about NTDs. Some work in isolated professions with little access to others who might share such information.

People reported that both men and women potentially have equal access to information and messages through MDA announcements on local FM stations and the strategy of house-to-house administration of drugs (based on the pre-existing register).

Little information is shared with children or parents about possible side effects of the drugs for children or adults. Sometimes children and their parents are unprepared for the dizziness, fatigue, skin itchiness, and vomiting that comes with the ingestion of the drugs, which some male focus group participants claimed made them hesitant to take the drugs in subsequent MDAs. This study finding is supported by

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<sup>12</sup> Theiler RN et al. Emerging and zoonotic infections in women. *Infectious Disease Clinics of North America*, 1998;22:755-772



several other studies, which showed that experiences of adverse events among participants would sometimes affect compliance in future MDAs.<sup>13</sup>

### **Access to MDAs**

Most people noted that due to the nature of the MDA (which is door- to-door and school-based) it would not be possible to omit any groups. A CDD is required to keep a registry of every person who lives in a house or a family compound. Unless an individual is very ill, a physical or mental disability would and should not prevent that person from receiving the drugs. No CDD interviewed admitted to leaving a person with a disability out of an MDA; the CDDs also said they did not know anyone else who did this.

Mothers reported that pregnant and breastfeeding women miss out on ivermectin distribution, and because multiple pregnancies and subsequent time for breastfeeding can last several years, women are missing out on the drugs for that amount of time. Several mothers across the three regions reported that they had never taken ivermectin because they had been pregnant or breastfeeding every time an MDA occurred. This is concerning given that it does not match the official WHO and government guidelines as breastfeeding women should not be excluded from MDAs. This could have a real impact on coverage rates for women in Ghana if this understanding of the guidelines is nationwide.

Out-of-school children were reported to be more likely to miss school deworming campaigns.

People who have taken alcohol on the day of the MDA might not take the drugs, according to some of the CDDs, although this is not one of the official exclusion criteria. Most of the people identified as having had alcohol were men, although no findings nor data point to this having a major effect on MDA coverage.

Many CDDs reported trying to do their best to administer the drugs to everyone, despite many challenges. However, despite explicit guidance to watch everyone ingest the drugs, CDDs did not always practice this. Community members and some CDDs reported they would leave the drugs with women of the household if not everyone was home at the time of the visit. However, women admitted they could not always verify if men took the drugs. The CDD would nevertheless register that everyone in the household had taken the drugs.

A limited quantitative analysis was done for the three districts in Ghana visited during fieldwork (Ahanta West, Kpandai, and Sekyere Afram Plains) using coverage data by sex from USAID NTD Disease Workbooks (2012-2018) and prevalence data by sex from individual-level DSA data obtained from countries (See Appendix 2 Table 1 and Table 2 for details). The analysis shows that MDA coverage was significantly higher for females than males for LF treatment during three of the past four years (2015-2018) in Ahanta West (although it was significantly lower for females than males in 2017). However, in Sekyere Afram Plains, coverage was very low overall, but significantly higher for males than females for the three most recent years for which data was available for STH (2015–2017) and onchocerciasis (statistically significant in 2016 and 2018). It is difficult to determine the reasons for these differences—however one possibility is that breastfeeding women are being left out of MDAs due to incorrect

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<sup>13</sup> Krentel A, Fischer PU, Weil GJ. A review of factors that influence individual compliance with mass drug administration for elimination of lymphatic filariasis. *PLoS Negl Trop Dis*. 2013;7(11):e2447

training of CDDs or misconceptions of community members about breastfeeding contraindications with MDA, which could have a significant impact on coverage given that breastfeeding is almost universal in Ghana up to a child's first birthday and half of women breastfeed until age 2<sup>14</sup>. In addition, since data were not available for all diseases across all years, it was not possible to know whether other diseases in Ghana received unequal MDA coverage. It is interesting to note that there was no statistically significant difference in prevalence rates between the sexes for OV, SCH or STH for any of the years for which data was available in Ghana.

### **Compliance with MDAs and knowledge of NTDs**

It appears that the majority of men, women, and children are complying with the MDAs due to the system of preregistration, community sensitization, trust of the CDDs, trust in the government, and the perceived efficacy of the drugs. The MDAs have generally been successful according to both quantitative program coverage data and study participants. However, community members reported knowledge of others not taking the drugs and the reasons for this.

People generally believe that the drugs are effective in treating parasitic infestations. However, respondents had some misconceptions about how people contract the diseases and some misinformation about the drugs, which impacts their perception of risk and therefore willingness to comply with MDA. Many community members noted that adults and children often experience moderate to severe side effects from the drugs. This leads some people not to take the drugs or to believe something is wrong with the medications. Respondents in each region reported that some people reject the drugs because they believe the government is conducting a secret family planning campaign. This mistrust of government drugs is being reinforced by misinformation circulating on social media. Male and female community members as well as CDDs reported that men are more likely to refuse to take the drugs. Many do not see the drugs' immediate benefit and do not believe in the idea of taking medication for an illness you do not appear to have. People also think they are just being experimented on and that the drugs actually give them diseases. On the other hand, some men perceived the drugs improved their sexual performance. Some men said they felt stronger, more vital, after they took the drugs.

Some men said the drugs have been brought by white people to make their wives infertile. Others said since the drugs are given at no cost, they are not effective so there is no need to take them. Some said the drugs cause leprosy. Some associated the drug distribution with politics. If a CDD is a politically active person, some households will refuse to take the drugs if they see the CDD as coming from the other camp.

Some respondents had never known anyone with these diseases so they did not know why they should be taking the drugs.

Most participants could not explain how people contracted specific NTDs. Some attributed the diseases to witchcraft. Some community leaders and members said LF is acquired by stepping on cow dung. Most of the male Kpandai community leaders said that LF is infectious and people contract the disease by being close to the infected person. Female community leaders knew that SCH affects people who spend time in the water, especially boys who swim in streams. (The boys start getting blood in their urine and

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<sup>14</sup> Ghana Statistical Service (GSS), Ghana Health Service (GHS), and ICF International. 2015. Ghana Demographic and Health Survey 2014. Rockville, Maryland, USA: GSS, GHS, and ICF International

the parents know that something is wrong.) Female community members also knew that children who eat soil can get worms. They did not know what causes onchocerciasis, however. As mentioned earlier, these misconceptions around the causes of each disease could impact people's risk perception and therefore compliance with MDA.

Communities are not given a great deal of prior notice about the MDAs, and the time is very limited for the CDDs to properly educate people on the diseases and the drugs. CDDs and community health workers (CHWs) reported that irregular dates for the drug distributions is a major challenge. They may only be told ten days before an MDA is due to start that they have to mobilize the CDDs, conduct the training, and conduct awareness raising.

It is well known that pregnant women should not take ivermectin. Respondents in a couple of FGDs (with CHWs and mothers) reported that women sometimes do not admit to the CDDs they are pregnant and take the drugs to end their pregnancies. One woman said she knew someone who took the drugs while she was pregnant and subsequently had a miscarriage (It was not clear if the drugs caused the miscarriage). Male CDDs admitted that it is a problem when adolescent girls do not tell them they are pregnant. More information has to be provided to CDDs and women in the community about exactly what the possible effects could be if taken during pregnancy.

#### **Selection of CDDs and their perceived effectiveness**

In Ghana, most CDDs were selected by the community leaders without much element of volunteerism. While this is the process in each of the other countries as well, CDDs in Ghana reported not being consulted about taking on this role and not feeling like they were able to opt out leading to frustration and lack of motivation among some CDDs.

CDDs are usually well-respected members of their communities and are selected because of their reputation in the community. While national level training data showed more women than men being trained for this role, our experiences in the three research districts were the opposite. The general perception is that the CDDs do their job as intended, which is door-to-door distribution of drugs. They follow protocols and act with respect and professionalism. The work of CDDs for NTD MDAs was acknowledged across the board to be very challenging.

There is a widespread perception by some community members that the CDDs are paid a lot of money. As a result, CDDs are sometimes accused of financially benefiting from people's suffering. The CDDs explained during the FGDs that they try to dispel this false perception, but people do not believe them. They suggested that health workers could come to the community to explain that CDDs are not paid, and people would listen to them.

Female CDDs have more access to other females in very conservative homes, where men are not allowed to talk or mix with women. Women can confide easier in other women on issues considered private to them, such as pregnancy. Many respondents (both men and women) said that female CDDs express themselves much better than men, are more reliable, more patient, take more time to explain to men and women about what the diseases are, how the diseases affect people, why people should take the medicine, what will be the side effects of the drugs, and what people should do if they experience side effects. They said female CDDs meet their targets and have impressive record-keeping abilities. Female CDDs mentioned that male CDDs do not always know how to communicate effectively to people about the diseases and reasons people should take the drugs, and this can be a barrier to

access and treatment. Additional training on interpersonal communication skills could be one way for the project to improve this as well as encouraging more women to volunteer as CDDs.

CHWs in Sekeyere Afram Plains praised female CDDs. Their perception was that female CDDs are more reliable and dedicated. CHWs said that they work better than men, and their record keeping is more accurate. They also said that they always meet their targets in spite of the fact that they cannot work for extended hours like their male counterparts. CHWs indicated that women are more honest than some of the men. Women will tell you when they have not been able to finish the assignment, but male CDDs will sometimes lie to their supervisors, according to most CHW respondents.

The female CDDs mentioned that they have a lot of difficulty getting men to agree to take the drugs. The male CDDs did not mention the same difficulty; although it is possible that male CDDs were less willing to admit that males might refuse to take drugs from them, it was difficult to ascertain whether this was in fact the case.

When it is time to start planning for an MDA, the district health office lets the community leaders know volunteers should be chosen for the distribution. The CHWs share with leaders the selection criteria for CDDs. These include “must be able to read and write” and “must be honest.” By far the most important skill cited for a CDD was literacy. Some of the male and female CDDs selected are the only ones in the village who can read and write, which also limits the volunteerism aspect of CDDs.

Despite the ringing endorsement by community members and MDA supervisors (across the districts) of female CDDs’ skills, community leaders reported a clear preference for choosing male CDDs. When asked why people thought there were more male CDDs in the communities, both men and women said they thought men can do a better job than females traveling to hard-to-reach areas and that women are “weaker” than men and should stay home to take care of the children.

At the national level, data on numbers of CDDs trained in 2014, 2015, and 2017 (our proxy for CDDs employed) showed a higher number of female CDDs than males in Ghana. However, district health officials confirmed that this was not the case in the three districts visited for this study. Some respondents in international organizations based in Accra even questioned the national-level data, saying they have never seen more female than male CDDs in Ghana.

### **Gender-related benefits or challenges to performing the role of CDD**

CDDs are often well respected by the communities and have a say in community issues. They are seen as role models and are viewed as providing a vital service to the community. For some men, being a CDD is a pathway to becoming a revered community leader. When female CDDs were asked if their husbands were supportive of their work as CDDs, they all said yes. Some of their husbands are also CDDs so they work together on the distribution.

When female CDDs were asked why they do this work even though it is physically demanding, can be stressful, and does not pay any salary, they said they feel satisfaction in helping fellow community members stay healthy.

Some of the challenges noted by CDDs, included receiving a very small transport allowance that is less than that paid by other campaigns (such as for malaria net distribution or polio vaccinations), which can

be more of a barrier to women than men as women have many more demands on their time, and therefore taking on an unpaid role can be seen as not worth the time investment.

Additionally, the distances CDDs must walk are sometimes very far, and they do not have the proper attire. They need boots, raincoats, and other means of transportation. They sometimes have to cross rivers on foot. This is often more challenging for women, who often have less access to motorbikes or bicycles.

Pregnant women are not supposed to take ivermectin and CDDs must ask women if they are pregnant in order to prevent this. In Sekeyere Afram Plains, CDDs reported that it is difficult for a woman to share this intimate information with a male CDD, especially if she is in the early stages of pregnancy and has not shared the news widely. The male CDDs called these women “shy.” Male CDDs in this district, and presumably in other more conservative areas, are generally not able to enter into homes if only the women are home.

### **Recommendations for Ghana:**

1. Conduct sensitizations on gender equality, sexual harassment, and the value of encouraging more women to volunteer as CDDs with NTD program officials from the MOH and districts.
2. Through sensitizations during recruitment calls for new CDDs, highlight the benefits of women serving as CDDs to both the community and the family, including ability to reach women more effectively in conservative communities. Through these sensitizations, encourage women to volunteer for these roles, given their interest and aptitude for the work and the opportunity it provides to serve in additional community health-related roles. This should include increasing flexibility regarding literacy in the selection criteria to become a CDD (particularly if CDDs work in pairs where one CDD is literate), and add “soft” skills such as good communication, patience, etc. Emphasize that the role of CDD is voluntary and a woman (or a man) should not be pressured to apply if she is not interested.
3. Pilot an increased outreach with community members and stakeholders in the form of “durbars” or community meetings (particularly in areas with high rates of refusal) to increase acceptance of the drugs, particularly among men. Having CDDs or other volunteers meet formally with stakeholders before MDAs to sensitize them—and gain their support in reaching any particular groups of refusers or groups likely not to be reached—can serve to improve acceptance among men and adolescents. (See additional details above on “MDA Champions.”). These outreach activities would be timed in such a way as to optimize chances of reaching men, such as during the evenings and in places where men congregate, such as mosques.
4. Pilot an increase mass media (radio) campaigns in all areas with low MDA coverage on NTDs and MDAs to increase awareness and acceptability, particularly for men who seem to be missing these messages more often than women.
5. Increase emphasis during training of CDDs and CDD supervisors about the importance of communicating the side effects of each NTD drug so that male recipients, in particular, will be informed and less likely to refuse drugs during the subsequent MDA. Trainings should also add

include heavy emphasis on the importance of CDDs ALWAYS directly observing treatment due to the observed issues with this in visited sites.

6. Trainings for CDDs and MDA supervisors do not include any mention of gender or social inclusion-related considerations, aside from not providing the drugs to pregnant women and in Ghana there seems to be confusion around the eligibility of breastfeeding women. The NTD program trainings should be revised to include discussion around interpersonal skills, gender-related considerations, GBV, sexual harassment, and provide formal guidance for CDDs and MDA supervisors on the inclusion of people with disabilities—particularly those living within marginalized settlements, and the eligibility of breastfeeding women. Include methods for measuring individuals who are unable to stand and be measured on a dose pole.
7. Increase use of appropriate visual aids depicting information on how the diseases are contracted and how they manifest, among CDDs and other MDA workers to help inform populations on NTDs, both during and before distributions.
8. Pilot increasing the time districts have to prepare for the MDAs. District health offices are given a couple of days to prepare for an MDA. They request at least two weeks, if not three to four weeks.
9. Adjust the number of CDDs from one MDA to the next, in accordance with population growth, to ensure that densely populated areas have more CDDs compared to more rural areas which may not need as many CDDs.
10. Collect sex-disaggregated data on current, active CDDs to determine the numbers of women and men serving as CDDs to compare to the sex-disaggregated CDD training data to determine the validity of using CDD training data as a proxy for active CDDs in Ghana.
11. Increase the incentives for male and female CDDs, especially for those who must travel long distances over difficult terrain, by providing life jackets (for those having to cross rivers or large streams to do their work), torch lights, raincoats, rainboots, bicycles, bags to carry the drugs, and advocate for the MOH to pay transport allowances.
12. Provide ID cards or badges to formalize their role and provide them with a greater level of recognition. IDs were requested by CDDs as a sign of this recognition and an indication that they have some authority. Provide T-shirts to better identify them to the community. Provide certificates of appreciation from the district health office to recognize many years of work well done.

## **Sierra Leone Findings**

### **Policies and regulations**

Sierra Leone enacted the Disability Act in 2011, which established the National Commission for Persons with Disability. The Commission is charged with the responsibility of fighting all forms of discrimination against persons with disability and ensuring the enhancement of equal opportunities for persons with

disability among other matters. In terms of gender-related policies, Sierra Leone enacted in 2007 the Domestic Violence Act and Sexual Offences Act, the Registration of Customary Marriage/Divorce Act and the Devolution of Estates Act. However, it is generally understood that these policies have not been effectively implemented nationally.

In Sierra Leone, the NTD control policy includes provision of MDA to men, boys, women, girls, and persons with disabilities. However, there are no specific targets or policies around MDA coverage by sex or disability. Trainings for CDDs and MDA supervisors do not include any mention of gender or social inclusion-related considerations, aside from not providing the drugs to pregnant women. The government does not currently have a policy on gender equity and social inclusion (GESI) in the workforce or for the health volunteer cadres. Such a policy could help address barriers to women serving as CDDs and affect the number of women serving in this role.

### **Patterns of power and decision making**

Throughout the three districts where the gender analysis data collection took place, most community members and leaders agreed that household decision making, including all decisions related to healthcare such as participation in MDA, is the role of the male head of household, but often in consultation with his wife. In cases where the head of household is unavailable, another family member (such as an uncle, mother-in-law, or father-in-law) will make decisions, particularly related to health. Some female respondents also said that if their husband were unavailable or had died, they would be the primary decision maker in the household.

### **Differential impacts of NTDS on women and men**

Almost universally, participants told us that women are responsible for caring for the children and other family members who are not able to care for themselves. If a woman becomes infected with an NTD that leads to disability, she will often be rejected by her husband since she is unable to carry out her caretaking and household responsibilities. Women with disabilities also face poor economic prospects and often must leave the community to beg in urban areas. This is also the case for men. However, the social impact of a disability such as lymphedema can be more dramatic for women, who are more likely to avoid being seen in public. Men with hydrocele, we were told, can often still go out into the community and interact with people outside the home. Overall, the social and economic impacts of disability can be overwhelming for both men and women. But disabled men often have some social advantages over disabled women and be cared for longer within the household by wives and children.

### **SBC messaging and access to information about NTDs and MDAs**

Almost all community leaders and members reported that both men and women are well-informed about MDAs—although not necessarily about disease transmission and drug side effects—because the NTD program uses multiple platforms to reach people with messages about the drug distributions. In Sierra Leone, a Knowledge, Attitudes, and Practices (KAP) survey conducted by the project found large percentages of both men and women had heard messages about MDAs on radio in the past. The KAP survey results showed that the majority of men and women said that they would prefer to hear about MDAs from CDDs/CHWs or radio. Women are also home or in the community much of the time and are therefore more likely to be reached with messages through multiple sources (e.g., from health workers and town criers). Men who are frequently absent from the community are more likely to miss these messages, particularly in urban areas. During FGDs in Kenema and Western Area some fathers claimed to have never heard about the MDAs.

Another qualitative study that took place in Ghana around the same time found that sensitization was an issue in Ghana:

*“Over ten years of MDA in Ghana and Nigeria, the level of engagement and commitment to information and sensitization activities at varying levels of the health system has drastically reduced due to apathy and the assumption that community members are already well informed. Informants described that despite a long legacy of implementation, the programme does not consider that populations have changed and increased with younger community members and inward-migration most of whom do not know the purpose of the MDA and what the drugs are meant for.”<sup>15</sup>*

### **Access to MDAs**

According to both quantitative program coverage data as well as qualitative reporting by study participants, in general, most people who are eligible to participate in MDAs are reached—due in large part to the dedication of the CDDs who go to multiple locations (schools, markets, mosques, and house to house) on weekends, evenings, or early mornings to accommodate the schedules of people who are away from home for most of the day. Government officials, MDA supervisors, CDDs, and community members agreed that CDDs reach most in-school and out-of-school children, people with disabilities, and women. In general, men are reached on par with women. However, men are more likely to be missed in urban and border areas and in fishing communities, where they are often away from home for days or weeks at a time. Shortages of drugs are reportedly sometimes a problem in urban and border areas having high levels of movement and migration that make accurate estimates of eligible populations difficult. In both Kenema and Koinadugu, each of which has had two failed pre-TAS, there is a lot of cross-border travel for both commerce and social reasons. Commerce-related travel is almost exclusively done by men and therefore more likely to impact MDA access.

In Sierra Leone, MDAs are conducted differently in towns and cities, where nursing students or other non-CHWs conduct the distributions. These distributors are often not from the community and sometimes they lack any relationship or trust with community members. This sometimes appears to impact their ability to reach all the eligible household members, especially men, according to the CDDs working in urban communities. One male respondent from an urban neighborhood in Kenema said, “The CDDs are concentrating more in the homes and forgetting us in the business places. Like the office where I am working, they have never been there, and I do not have time to go and meet them. So for us in the business places, access is very low.”

One CDD in an urban area reported that he did not distribute drugs in his catchment area in the part of the community with people having disabilities. Other CDDs reported no problems distributing the drugs to people with NTD-related or any other physical disabilities.

A limited quantitative analysis was done for the three districts in Sierra Leone visited during fieldwork (Kenema, Koinadugu and Western Area) using coverage data by sex from USAID NTD Disease Workbooks (2012-2018) and prevalence data by sex from individual-level DSA data obtained from countries (See Appendix 2 Table 1 and Table 2 for details). In all three districts where the study was conducted, available program MDA coverage data over the past four years were very similar for men

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<sup>15</sup> Dean L, Ozano K, Adekeye O, Dixon R, Fung EG, Gyapong M, et al. Neglected Tropical Diseases as a ‘litmus test’ for Universal Health Coverage? Understanding who is left behind and why in Mass Drug Administration: Lessons from four country contexts. PLoS Negl Trop Dis. 2019. 13(11): e0007847.



and women. There were no statistically significant differences across the MDAs conducted, with the exception of statistically significant higher coverage rates for men as compared to women in 2013 and 2015 for LF and STH treatment. However, data were not available for all diseases across all years, so the analyses were limited. Again, it is interesting to note that there was no statistically significant difference in prevalence rates between the sexes for SCH or STH for any of the years for which data was available in Sierra Leone.

### **Compliance with MDAs**

In Sierra Leone, MDAs are a long-standing and well-established countrywide program. Some of the CDDs in Sierra Leone who participated in the FGDs, particularly in Koinadugu district, had supported the MDAs for over a decade. Most community participants, especially in rural areas, expressed gratitude for the drugs. CDDs, MDA supervisors, and Ministry staff said they had themselves experienced positive health effects and had seen improved health across their communities. Many community members as well as CDDs and NTD program officials mentioned that when MDAs first began many years ago, there was a great deal of mistrust about the drugs, and high levels of negative side effects were also reported. Male participants spoke about negative side effects more often than women did, and also mentioned a perception of the positive effect of the “oncho drugs” on sexual performance. Most of the men said they only experienced negative side effects the first time they took the drugs, making them hesitant to take the drugs again, but most had taken them in following years with no problem. Although only a handful of participants in Sierra Leone admitted to refusing the drugs, all of these were men. They said they refused because they mistrusted the drugs or feared side effects and did not understand the need to take medication, particularly if they did not feel ill. Some men reported that they would be more likely to take the drugs if the CDDs took more time to explain the potential side effects—so that they knew what to expect.

Ministry officials, NGO staff, and district health NTD focal points said in the past there was resistance among Fulani cattle herders in northern districts of the country. However, it appears this has improved in recent years because we did not hear about it in our discussions with CDDs or community members in Koinadugu, many of whom were Fulani. The NTD program is now targeting messaging to Fulani tribal leaders and trust seems to be improving, according to Act | West program staff in country. Reasons given for resistance in the recent past, according to CDDs and government and program key informants, included conservative gender norms (women felt they could not take the drugs if their husbands were not present to give permission); men telling their wives not to take the drugs because of a fear they would cause sterility; and distrust of members outside their ethnic group (if the CDD was of a different ethnic group).

Women who aren’t sure if they are pregnant will not take the drugs. A few CDDs said some girls and adolescent boys have resisted because they feared the drugs would make them sterile, indicating a need for increased messaging on NTDs and the drug campaigns.

### **Selection of CDDs and their perceived effectiveness**

CDDs are selected in Sierra Leone by community leaders, except in urban areas where nursing students are recruited from local nursing schools. The only policy is that CDDs should be permanent residents of the communities in which they work. However, one district health official felt they should be selected by the community and the community should take care of motivating the CDDs, although in practice communities do not provide payments or motivations to the CDDs. Because the distribution/treatment and reporting are relatively simple, CDDs do not have to be fully literate to qualify, but they do have to

be able to fill in the registers properly. Most CDDs are also CHWs, but since there are not enough CHWs to do all the distributions, CDDs are also recruited through other volunteer cadres such as traditional birth attendants.

The vast majority of CDDs in Sierra Leone are male. The reasons given are that women are busy with farming and household responsibilities; they haven't been prioritized for schooling (disadvantaging them for CDD work and other jobs); and some husbands are jealous or disapprove, particularly when there is a need to travel outside the immediate community or work late hours to complete the distributions. Several CDDs said the small incentive payments (or lack of incentives) are a greater barrier for women, due to their numerous other responsibilities.

Despite the relatively few female CDDs, views of their performance were overwhelmingly positive. Most FGD and KII respondents felt that female CDDs perform as well or better than men. Many people felt that female CDDs are more persuasive and patient, therefore increasing the case both for encouraging more women to volunteer as CDDs and for including training on interpersonal communication for all CDDs.

### **Gender-related benefits or challenges to performing the role of CDD**

In Sierra Leone, CDDs conduct distributions mainly through the schools and from door to door. In addition, they often seek out community members in spots where people congregate (e.g., in markets and sporting events). Both male and female CDDs felt that the main benefit of serving in this role is respect by the community and feeling good about helping their neighbors and friends. Both groups reported that being CDDs elevated their social status. Many were selected to be CHWs when the country rolled out the new CHW program about two years ago.

Both men and women CDDs also experienced challenges in the role, including the following: travelling long distances by foot or bike to deliver the drugs, often in heavy rain; insufficient supply of drugs (particularly in urban and border communities); overwork due to insufficiency of CDDs; too little notice to access the schools for distributions; difficulty accessing remote and mountainous communities (particularly in the rainy season); skepticism and physical barriers such as gated compounds (especially in urban areas); and difficulty in Fulani communities (where women will not accept male CDDs or CDDs from a different tribe or ethnicity).

While both men and women CDDs expressed frustration with the low incentives (or lack of incentives), this was seen as a bigger barrier for women, given the numerous demands on their time. A couple of female CDDs mentioned experiencing sexual harassment, particularly while working in communities in which they were less familiar. Additionally, the long distances and long hours were seen as a larger barrier for women as well since men often have access to motorbikes, bicycles, and fewer household responsibilities to work around.

### **Recommendations for Sierra Leone:**

1. Advocate for specific MOH targets or policies around MDA coverage by sex or disability that align with national gender ratios and disability statistics.
2. Conduct sensitizations on gender equality, sexual harassment, and value of nominating more women as CDDs with NTD program officials from the MOH and districts.

3. Through sensitizations during recruitment calls for new CDDs, highlight the benefits of women serving as CDDs to both the community and the family, including ability to reach women more effectively in conservative communities. Encourage officials/leaders to nominate more women for these roles, given their interest and aptitude for the work and the opportunity it provides to serve in additional community health-related roles. This should include increasing flexibility regarding literacy in the selection criteria to become a CDD (particularly if CDDs work in pairs where one CDD is literate), and add “soft” skills such as good communication, patience, etc. Emphasize that the role of CDD is voluntary and a woman should not be pressured to apply if she is not interested.
4. Pilot an increased outreach approach with community members and stakeholders (particularly in areas with high rates of refusal or low program coverage) to increase acceptance of the drugs. Having CDDs or other volunteers meet formally with stakeholders before MDAs to sensitize them—and gain their support in reaching any particular groups of refusers or groups likely not to be reached—can serve to improve acceptance among men and adolescents (see additional details above on “MDA Champions”).
5. Increase emphasis in CDD and CDD supervisor training about the importance of communicating the side effects of each NTD drug so that male recipients, in particular, will be informed and therefore less likely to refuse drugs during the subsequent MDA. This will be done through advocacy and technical assistance to the MoH and may include formalization of training materials.
6. Provide CDDs with raingear to make it easier to conduct the distributions—particularly for women, some of whom expressed a greater need for these, given they often have fewer transportation options than men because of norms around women driving mopeds or bikes. Raingear would make it more feasible for women, especially, given the difficult terrain and that MDAs often take place in the rainy season. Raingear would benefit male CDDs as well, and availability might increase overall interest in the CDD role.
7. Advocate for the MOH to provide transportation reimbursement to CDDs who have very large catchment areas and must travel especially long distances. It is often less feasible or acceptable for women to ride bicycles or motorbikes, so having to serve in locations far away (and without transportation reimbursement) provides a greater barrier for women to support MDAs outside their own community.
8. Recruit and send CDDs to areas in which they speak the local language and provide CDDs working outside their home community with badges to increase their profile. This is particularly important in areas with high rates of past refusal (e.g., Fulani communities in urban areas).
9. To the extent possible, synchronize MDAs in Sierra Leone with those taking place in Guinea (also an Act | West country) and Liberia to improve coverage among nomadic populations—particularly among male traders. Train border officials as CDDs to conduct distributions at border crossings.
10. Trainings for CDDs and MDA supervisors do not include any mention of gender or social inclusion-related considerations, aside from not providing the drugs to pregnant women. The NTD program trainings should be revised to include discussion around gender-related considerations, GBV, sexual harassment, and provide formal guidance for CDDs and MDA supervisors on the inclusion of people with disabilities—particularly those living within marginalized settlements. Include methods for measuring individuals who are unable to stand and be measured on a dose pole, as well as messages about the importance of including stakeholders with disabilities and community leaders within settlements consisting of people

with disabilities to increase awareness of MDAs and acceptability. Ensure CDDs who are selected are sensitized to treat those individuals/communities.

11. Increase use of appropriate visual aids among CDDs and other MDA workers to help inform populations on NTDs, both during and before distributions, translated into local languages.
12. Conduct or adapt mass media (radio) campaigns in all urban areas on NTDs and MDAs to increase awareness and acceptability, particularly for men who seem to be missing these messages more often than women.

## **Côte d'Ivoire Findings**

### **Policies and regulations**

The Ministry of Health does not consider gender as a factor in its approaches to NTDs, aside from the exclusion of pregnant women from the distribution of ivermectin.

The law in Côte d'Ivoire states that 30 percent of governmental positions must be filled by women. However, this law technically does not apply to CDDs since they are classified as volunteers.

### **Patterns of power and decision making**

Mothers, grandmothers, and fathers agreed that in Côte d'Ivoire women are responsible for taking care of children in the home, but the man decides if a woman can take a sick child to the health facility and the man will be responsible for paying for any medication. Community members were quick to say that while it is important to inform the husband, permission is not more important than the health of the child. Most mothers and fathers agreed that if the child is gravely ill, the mother can take the child without waiting for permission. Most participants agreed that the male head of household is the primary decision maker about all household matters, including matters such as participation in MDA and women's participation in the workforce (paid or unpaid).

### **Differential impacts of NTDs on women and men**

There were mixed beliefs among mothers, grandmothers, fathers, and community leaders about whether men or women are more affected by NTDs. Some said that women are more exposed to NTDs because of their roles as mothers, because they work on the land, and because they are generally poorer and more vulnerable than men. Others said NTDs affect men more. As discussed in earlier sections, the misconceptions around perceived vulnerability to each NTD or causes can have an impact on people's willingness to participate in MDA.

Respondents in the community of Divo, in contrast to Touba and Korhogo, had greater awareness of LF and onchocerciasis, better understanding of how people contract the diseases, knew more people who had the diseases, and actually wanted more information about the diseases. In Touba, there was much less awareness of how people contracted the diseases. Elephantiasis (LF) and trachoma were the most well-known of the diseases, but generally people did not know much about how people got the diseases and they did not know many people who had them.

### **SBC messaging and access to information about NTDs and MDAs**

Information is shared about upcoming MDAs in public places. The griot also informs the village. Griots are trained before each campaign. However, women are more likely to hear messages from griots

because they are more likely to be in town doing trading; men are more likely to be away from the village for farming or work. Women who receive information about the MDAs pass it on to their husbands. It is easier to share information about upcoming MDAs in smaller villages than in towns with larger populations.

Posters were visible in health facilities in all three districts. CDDs reported that they carry brochures with pictures depicting the diseases, explain to community members how the diseases are contracted, and provide general information about the NTDs and drugs. However, this was contradicted by most community members. They reported having seen posters in health facilities but not receiving any in-person sensitization—except in Divo where community men appeared to be better informed about NTDs and transmission. There was little understanding of how people got the diseases and few people knew anyone who was afflicted. Among community members, the only people who seemed to know anything about NTDs were those who knew someone suffering from a disease.

Overall, people in the communities included in the study have not been properly informed about what the MDAs are for. However, they trust the health care workers and volunteers, so most reported that they take the drugs. When asked for suggestions to improve compliance with the MDAs, almost all groups and interviewees (including MOH officials, community leaders and members, CDDs, and providers) said more sensitization, including visual aids, are needed to convince people of the importance of taking the drugs.

### **Access to MDAs**

CDDs for the most part said that they distribute the drugs to everyone and that no one is missed, which generally aligns with the coverage data, although in almost all districts in 2018, coverage was higher for females than males. Both male and female CDDs spoke of their sometimes-Herculean efforts to ensure they watch everyone ingest the drugs. Both CDDs and community members said CDDs are flexible and will work around peoples' schedules, including coming back to households late in the evening, especially to reach men (which is more challenging due to men's work and travel schedules).

Everyone agreed that it is unlikely people with disabilities are missed during the MDAs because the door-to-door campaign makes drug administration accessible. When asked how they measure people who cannot stand against the dose pole, some CDDs said that they estimate the height of the person by comparing with another person of the same age. While it appears that CDDs have improvised ways to measure people who are unable to stand, there is lack of formal guidance and standardization, which can lead to incorrect dosing or compromising the dignity or safety of people with mobility-related disabilities.

A limited quantitative analysis was done for the three districts in Ivory Coast visited during fieldwork (Divo, Korhogo and Touba) using coverage data by sex from USAID NTD Disease Workbooks (2016-2018) and prevalence data by sex from individual-level DSA data obtained from countries (See Appendix 2 Table 1 and Table 2 for details). Divo showed higher coverage (although not statistically significant) among females than males during the past three years (2016-2018) for LF and onchocerciasis treatment. In Korhogo, there was statistically significant higher MDA coverage among females than males for LF and onchocerciasis treatment in 2018, but no statistically significant difference during the previous year (which was the first year of the MDA that we have data for). In Touba, there was statistically significant higher coverage among males than females in 2018 for LF, OV and STH; however, this could be an anomaly, because the available data from previous years showed higher coverage among females. While

the data show some interesting findings, it is difficult to draw overall conclusions, given the wide variance from year to year in most districts. The project only has access to MDA coverage beginning in 2016, and data were not available for all diseases in all three years. The lower coverage among men in Korhogo in 2018 and Divo from 2016–2018 may be due to compliance issues or men being missed due to migration or work. Again, it is interesting to note that there was no statistically significant difference in prevalence rates between the sexes for OV for any of the years for which data was available in Ivory Coast.

### **Compliance with MDAs**

For those who experienced negative side effects from any one of the MDA drugs, it often affected their willingness to take the drugs on a subsequent MDA. CDDs cited many difficulties convincing people to take the drugs if they experienced particularly bad side effects, which is understandable, however improving communication around potential side effects before MDA can ease concerns. According to the community members, these include general itchiness, headaches, and sleepiness. Community members did not appear to know that the itchiness is an indicator of the drug's effectiveness in killing parasites in the body. Information linking side effects with the level of efficacy is likely to improve people's acceptance.

Some CDDs said men sometimes resist taking the drugs for a variety of reasons, including that they do not believe in taking medication if they do not feel sick, they are suspicious of the drugs, and they think the drugs are a form of imposed family planning. This tracks with findings from other research demonstrating that in some cases men are often more suspicious of MDA and more likely to comply with treatment<sup>16</sup>. This mistrust among men can also impact access to treatment for their wives and children if they refuse to let them participate as well. In this case the true gender dimensions around access and compliance may be hidden within the data since it wouldn't be just men who are left out.<sup>17</sup> An anecdote was told about a griot in Korhogo who promoted the MDAs to community members but then (subversively) told male friends not to take the drugs. However, this appeared to be an isolated incident.

Some CDDs said that people from tiny outlying villages are more hesitant and refuse drugs more often than those from less isolated villages. Some CDDs and supervisors reported men are more likely to refuse the drugs than women; men sometimes say they fear the drugs will make them infertile. An increase in mass media or other forms of sensitization, particularly in areas where there are noted higher refusal rates, would potentially decrease mistrust and improve compliance.

There were reports of some people with NTD-related disabilities refusing to take drugs from the CDDs because they thought it was too late for them to benefit from them. This could also be addressed with increased sensitization directly by CDDs or through mass media.

### **Selection of CDDs and their perceived effectiveness**

The selection process for CDDs varies from district to district in Côte d'Ivoire. It appears that CDDs are selected by community leaders more often in rural areas. In larger towns, the district health office puts

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<sup>16</sup> Rilkoff H, Tukahebwa EM, Fleming FM, Leslie J, Cole DC: Exploring Gender Dimensions of Treatment Programmes for Neglected Tropical Diseases in Uganda. *PLOS Neglected Tropical Diseases* 2013, 7:e2312.

<sup>17</sup> Dean L, Ozano K, Adekeye O, Dixon R, Fung EG, Gyapong M, et al. Neglected Tropical Diseases as a 'litmus test' for Universal Health Coverage? Understanding who is left behind and why in Mass Drug Administration: Lessons from four country contexts. *PLoS Negl Trop Dis*. 2019. 13(11): e0007847.

out a call for volunteers, and candidates respond by coming to the district health office to apply. All CDDs interviewed were clear that, in this latter process, the first criterion is to pass a literacy test. The district health office appears to consider literacy the most important factor in selecting CDDs, and low literacy among women in rural areas was cited as one of the primary reasons there are fewer females than males. However, in the town of Touba, the director of the district health office said he usually sees more female CDDs submitting applications. He felt that the main reason is that CDDs are not paid, and fewer men are interested in doing unpaid work.

All community members praised the communication skills of female CDDs. Both men and women agreed that community members are more likely to listen to and trust women CDDs and that some more conservative women are more accessible to female CDDs.

Communities generally respect CDDs and respondents did not have strong views about the effectiveness of female CDDs over male CDDs. Some male facility-based providers said women are not up to the role of being CDDs and that they are not always good workers. However, this sentiment was not echoed by community members or leaders.

Both mothers and fathers said that women do not have time to volunteer as CDDs because of their household chores or that their husbands would disapprove. A few expressed concern about the safety of women traveling alone in rural areas—especially because they often walk, whereas men more often have access to motorbikes to travel between communities.

#### **Gender-related benefits or challenges to performing the role of CDD**

Generally, CDDs said they feel respected for the work they do. However, they cited many challenges. These included: the large geographic areas they must travel to reach populations; the hot or rainy weather they must endure; some general pushback from men about taking the drugs; and the few incentives provided for their work.

Female CDDs who traveled together in pairs mentioned safety issues; female CDDs paired with male CDDs were less likely to cite such concerns. Female CDDs complained they are sometimes harassed by community men if they are working in a remote area, and they said they do not feel comfortable traveling without a male CDD in the evening.

#### **Recommendations for Côte d'Ivoire:**

1. Conduct sensitizations on gender equality, sexual harassment, and value of communities supporting more women serving as CDDs (including allowing for more flexibility around literacy requirements) with NTD program officials from the MOH and districts (which they will be expected to flow down to MDA supervisors, and CDDs through district-level officials during formal trainings of CDDs).
2. Through sensitizations during recruitment calls for new CDDs, highlight the benefits of women serving as CDDs to both the community and the family, including ability to reach women more effectively in conservative communities. Encourage officials/leaders to nominate more women for these roles, given their interest and aptitude for the work and the opportunity it provides to serve in additional community health-related roles. This should include increasing flexibility regarding literacy in the selection criteria to become a CDD (particularly if CDDs work in pairs).

where one CDD is literate), and add “soft” skills such as good communication, patience, etc. Emphasize that the role of CDD is voluntary and a woman should not be pressured to apply if she is not interested.

3. Trainings for CDDs and MDA supervisors do not include any mention of gender or social inclusion-related considerations, aside from not providing the drugs to pregnant women. The NTD program trainings should be revised to include discussion around gender-related considerations, GBV, sexual harassment, and provide formal guidance for CDDs and MDA supervisors on the inclusion of people with disabilities. Include methods for measuring individuals who are unable to stand and be measured on a dose pole.
4. Pilot an increase in outreach with community members and stakeholders (particularly in areas with high rates of refusal) to increase acceptance of the drugs. Having CDDs or other volunteers meet formally with stakeholders before MDAs to sensitize them—and gain their support in reaching any particular groups of refusers or groups likely not to be reached—can serve to improve acceptance among men and adolescents (see additional details above on “MDA Champions”).
5. Conduct or adapt mass media (radio) campaigns in areas where there is noticeably higher refusal or lower coverage on NTDs and MDAs to increase awareness and acceptability, particularly for men who seem to be missing these messages more often than women.
6. Provide CDDs with hats, MDA-branded shirts, and/or bags for the drugs to make it easier to conduct the distributions. Additionally, we can provide CDDs working outside their home community with badges to increase their profile and standing. Women, especially, expressed greater need for these given they often have fewer transportation options than men because of norms around women driving mopeds or bikes. These could make drug distribution easier and more attractive (for women in particular) for a couple of reasons. Shirts and hats with an identifying logo or ID cards provide additional legitimacy to the CDD position and allow CDDs to be readily identified by community members. Bags also help CDDs carry the drugs from place to place. These materials would also benefit male CDDs, and availability might increase overall interest in the CDD role.
7. Advocate for transportation reimbursement to CDDs who have very large catchment areas and must travel especially long distances. It is often be less feasible or acceptable for women to ride bicycles or motorbikes, so having to serve in locations far away (without receiving transportation reimbursement) creates a greater barrier for women to support MDAs outside their own community.
8. Increase use of appropriate visual aids among CDDs and other MDA workers to help inform the populations about NTDs, both during and before distributions. While we saw these posted at health facilities in the sites we visited, it appears that many people had never been shown them in the context of MDA or explained them. Additionally, it is less likely that men have seen them at all since they are less likely to visit the health facility.



## IMMEDIATE NEXT STEPS

1. Obtain feedback/comments on this document from USAID and country teams (the latter only if provided). Revise and finalize this document (as a stand-alone deliverable).
2. Hold discussions with USAID to present targeted ideas for program changes and obtain preliminary feedback before engaging with countries.
3. Organize in-country consultation workshops where possible, prioritizing the three countries where the qualitative research was conducted to validate the data and request feedback and buy-in with NTDPs on the recommendations.
4. Discuss and finalize with USAID which activities will be added to FY20 and later workplans and how the activities will be funded.
5. Identify cost implications of these recommendations and revise country workplans for FY20 and beyond to reflect agreed-upon activities.

## DRAFT ACTIVITY MATRIX

Activity	Responsible party	Timeline	Resources required
Finalize strategy with USAID, integrating USAID feedback	Jennifer Arney, Andrea Bertone, Diana Stukel, and Bolivar Pou	January 2020	LOE
Hold discussion with USAID to present targeted ideas for changes to programs to obtain preliminary feedback before engaging with countries	Jennifer Arney, Andrea Bertone, Diana Stukel, Bolivar Pou	Feb-March 2020	LOE
Conduct country consultations	Jennifer Arney, Andrea Bertone, in-country program and NTDP staff	April-June 2020	LOE, possible travel costs
Revise workplans	Act   West program staff	May-August 2020	LOE

## APPENDIX 1: SAMPLE FGD GUIDE

### FGDs for community members (mothers and grandmothers of children aged 6-15 years)

- Whose responsibility is it to take care of the children in your family?
- Who makes decisions about child-care in your family?
  - If your child/grandchild is sick and must go to the health clinic, whose decision is it that the child should go to the clinic?
  - Do you need to ask your husband for permission to go to the health clinic for your own health needs? To take the children/grandchildren?
- Do you need to ask for money?
- Do you go to the health clinic if you are sick?
  - Do you go alone or do you go with someone else?
  - If you go with your husband, are you moved to the head of the queue?
- Have you heard of these diseases: schistosomiasis, trachoma, soil-transmitted helminths, lymphatic filariasis, onchocerciasis? (use local names as necessary)
  - If yes, where did you learn about them?
  - Does the name of the disease have another meaning?
- Do you know anyone who has had any of these diseases? Male or female?
  - How do people get these diseases?
  - How did the disease affect the person(s)?
    - What were their experiences with the disease?
      - Symptoms
      - Experiences at the health clinic? Treated with respect or not
      - Stigma
  - How did the disease affect other family members?
- How did you find out about the drug distribution?
  - What has been your experience with the distribution of the drugs? Was it easy to participate? Did you have to go to a school, other location, or did someone come to your house? Who in your family participated in the distribution?
  - Have you taken the drugs? Did someone watch you ingest or you ingested alone?
  - If not, why not?
  - Have your children had difficulty taking the drugs?
  - Are there any side effects to taking the drugs?
  - Do you think the drugs will work as intended?
- Is there anyone you can think of who hasn't received the drugs? If so, why not?
- Have you or anyone in your family accessed services in the health facility for any of the diseases mentioned earlier?
  - What was the experience of that person in the health facility?
- Would any of these following reasons impact you from participating in an MDA?
  - Household responsibilities
  - Decision-making in the home
  - Ability to accept medicine from a male CDD
  - Pregnancy or breastfeeding status
  - Unsure whether the medicines are safe

- Do you think women and girls are at a higher risk for getting the diseases? If so, why? Do you think women and girls experience the diseases differently than men and boys?
- Do you know the community drug distributor who helps to eliminate the diseases?
  - What position do the CDDs have in the community? Are they well-respected?
  - Have they treated you with respect? Have they treated women with respect?
- Why do you think that the majority of the CDDs are men? (for Sierra Leone and Cote d'Ivoire)
- Why do you think the majority of CDDs are women? (for Ghana)
- Do you think men and women are equally capable and effective as CDDs?
- If yes, why? If not, why not?
- Are there any differences in how female or male CDDs do their jobs? Any challenges for male or female CDDs in particular in doing their jobs?
- Are there any differences in how community members respond to male or female CDDs, i.e. are community members more or less likely to take the drugs if it is a male or female CDD?

## APPENDIX 2: LIMITED QUANTITATIVE ANALYSIS ON THE DISTRICTS IN GHANA, IVORY COAST AND SIERRA LEONE VISITED DURING FIELD WORK

Table 1: Program Coverage Rates by Sex and Disease

Country	District	Year	LF		OV		TR		SCH		STH	
			Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
Ghana	Ahanta West	2013	60.3	60.3	.	.	.	.	.	.	.	.
Ghana	Ahanta West	2014	70.2	71.2	.	.	.	.	.	.	53.3	60.2*
Ghana	Ahanta West	2015	58.9	67.8*	.	.	.	.	.	.	.	.
Ghana	Ahanta West	2016	74.5	85.3*	.	.	.	.	.	.	.	.
Ghana	Ahanta West	2017	97.3	75.9*	.	.	.	.	.	.	.	.
Ghana	Ahanta West	2018	82.9	94.4*	.	.	.	.	.	.	69.9	72.3
Ghana	Kpandai	2013	95.7	95.7	87.5	92.9*	.	.	.	.	.	.
Ghana	Kpandai	2014	.	.	.	.	.	.	53.0	45.9*	81.7	92.2*
Ghana	Kpandai	2015	.	.	.	.	.	.	.	.	89.1	79.1*
Ghana	Kpandai	2016	.	.	.	.	.	.	.	.	99.2	98.8
Ghana	Kpandai	2017	.	.	69.3	63.9	.	.	.	.	.	.
Ghana	Kpandai	2018	.	.	.	.	.	.	.	.	.	.
Ghana	Sekyere Afram Plains	2013	.	.	.	.	.	.	.	.	.	.
Ghana	Sekyere Afram Plains	2014	.	.	.	.	.	.	61.1	60.1	61.1	60.1
Ghana	Sekyere Afram Plains	2015	.	.	.	.	.	.	.	.	88	77.5*
Ghana	Sekyere Afram Plains	2016	.	.	46.9	39.1*	.	.	.	.	53.5	35.7*
Ghana	Sekyere Afram Plains	2017	.	.	42.3	41.3	.	.	.	.	68.6	59.4*
Ghana	Sekyere Afram Plains	2018	.	.	52.3	43.5*	.	.	.	.	.	.
Ivory Coast	Divo	2016	84.9	86.8	85.5	88.4	.	.	.	.	.	.
Ivory Coast	Divo	2017	79.3	83.5	79.3	83.5	.	.	.	.	.	.
Ivory Coast	Divo	2018	92.4	96.4	92.4	96.4	.	.	.	.	.	.
Ivory Coast	Korhogo	2016	.	.	.	.	.	.	.	.	.	.

Ivory Coast	Korhogo	2017	88.9	88	88.9	88	.	.	.	.	.	.
Ivory Coast	Korhogo	2018	82.7	99.0*	82.7	99.0*	.	.	.	.	.	.
Ivory Coast	Touba	2016	.	.	88.3	97.6*	80.8	86	.	.	.	.
Ivory Coast	Touba	2017	.	.	.	.	93.6	97.9	.	.	.	.
Ivory Coast	Touba	2018	98.4	92.9*	98.4	92.9*	.	.	.	.	98.4	92.9*
Sierra Leone	Kenema	2012	.	.	97.3	98.4	.	.	.	.	.	.
Sierra Leone	Kenema	2013	.	.	.	.	.	.	.	.	.	.
Sierra Leone	Kenema	2014	.	.	99.3	94.0*	.	.	.	.	.	.
Sierra Leone	Kenema	2015	97.6	97	95.6	94.5	.	.	.	.	97.6	97
Sierra Leone	Kenema	2016	99.1	96.7	96.8	94.5	.	.	.	.	99.1	96.7
Sierra Leone	Kenema	2017	.	.	.	.	.	.	.	.	95.6	97.7
Sierra Leone	Kenema	2018	90.2	89.7	90.2	89.7	.	.	.	.	87	86.5
Sierra Leone	Koinadugu	2012	.	.	95.5	97.5	.	.	.	.	.	.
Sierra Leone	Koinadugu	2013	.	.	.	.	.	.	.	.	.	.
Sierra Leone	Koinadugu	2014	.	.	99	93.7*	.	.	.	.	.	.
Sierra Leone	Koinadugu	2015	97.4	97.6	95.3	95.4	.	.	.	.	97.4	97.6
Sierra Leone	Koinadugu	2016	.	.	95.8	94.3	.	.	.	.	.	.
Sierra Leone	Koinadugu	2017	96.5	97.7	96.5	97.7	.	.	.	.	93.8	95
Sierra Leone	Koinadugu	2018	86.3	86.9	86.3	86.9	.	.	.	.	83.2	83.7
Sierra Leone	Western Area Rural	2012	.	.	.	.	.	.	.	.	.	.
Sierra Leone	Western Area Rural	2013	98.7	90.5*	.	.	.	.	.	.	98.7	90.5*
Sierra Leone	Western Area Rural	2015	98.1	92.6*	.	.	.	.	.	.	98.1	92.6*
Sierra Leone	Western Area Rural	2016	.	.	.	.	.	.	.	.	.	.
Sierra Leone	Western Area Rural	2018	87.8	89.8	.	.	.	.	.	.	84.6	86.6

A two-sample two-sided test of proportions was conducted to examine the difference in program coverage rates by sex.

Null hypothesis: Male program coverage rate - female program coverage rate =  $\pm 0.05$

Alternative hypothesis: Male program coverage rate – female program coverage rate  $\neq \pm 0.05$

\* Female program coverage rate is significantly different from male coverage rate at 5% level.

**Table 2: Disease Prevalence Rates by Sex and Disease**

Disease type	Country	District	Year	Proportion Tested Positive		Number Tested	
				Males	Females	Males	Females
SCH							
	Ghana	Ahanta West	2015	25.0	24.0	24	25
	Ghana	Kpandai	2015	8.6	9.5	58	63
	Ghana	Sekyere Afram Plains	2015	0.0	0.0	24	24
	Sierra Leone	Kenema	2016	39.3	40.4	150	151
	Sierra Leone	Koinadugu	2016	33.3	32.0	150	150
	Sierra Leone	Rural Western Area	2016	1.1	0.0	88	111
STH							
	Ghana	Ahanta West	2015	0.0	0.0	18	23
	Ghana	Kpandai	2015	3.4	6.6	58	61
	Ghana	Sekyere Afram Plains	2015	4.2	0.0	24	24
	Sierra Leone	Kenema	2016	9.3	4.0	150	151
	Sierra Leone	Koinadugu	2016	23.3	16.7	150	150
	Sierra Leone	Rural Western Area	2016	14.0	14.4	86	111
OV							
	Ghana	Kpandai	2017	4.5	0.9	111	109
	Ivory	Touba	2016	3.4	0.7	149	145

A two-sample two-sided test of proportions was conducted to examine the difference in proportion tested by sex.

Null hypothesis: Proportion of females tested positive - proportion of males tested positive =  $\pm 0.05$

Alternative hypothesis: Proportion of females tested positive – proportion of males tested positive  $\neq \pm 0.05$

**No statistically significant differences were found at 5% level**



## APPENDIX 3: ACT TO END NTDS WEST GENDER ANALYSIS DESK REVIEW TROPICAL DISEASES | WEST

### Executive Summary

The United States Agency for International Development's (USAID's) Act to End Neglected Tropical Diseases (NTDs) | West program is conducting a two-phased gender analysis to determine how NTDs<sup>18</sup> differentially impact various populations; how gender norms and power differentials might impact NTD program results and how the program can help advance gender equality. Phase one of the gender analysis is limited to a literature review, drawing on published and grey literature, as well as an initial analysis of available quantitative data.

The phase one analysis found that, overall, literature on gender differences was limited and did not reveal findings that were generalizable across all 11 Act to End NTDs| West countries covered by the program<sup>19</sup> except in terms of biological differences in health and social impacts experienced by women and girls as a result of NTD infection, as well as higher rates of trachoma infection experienced by women and girls.

The analysis also found that in addition to increased health impacts from NTD infection, the social consequences of NTD infections are different for men and women and may disproportionately impact women, particularly when NTD infections negatively affect socially ascribed assets and attributes for femininity such as beauty, marriage, motherhood and childcare. Men are particularly impacted by the social impacts of hydrocele (scrotal swelling associated with lymphatic filariasis) described below. Women and men's, as well as boys' and girls' vulnerability to NTD infection is often related to their productive, reproductive and community gender roles, and NTDs have lasting impacts on educational and economic opportunities and outcomes which may differ for the sexes. However, while the literature shows that gender norms and roles may influence who gets infected, and the impact of that infection, the data around potential disparities or gaps in accessing information and treatment related to NTDs is less clear.

Across various countries implementing mass drug administration (MDA) programming for NTDs, MDA program coverage has been reported as largely equal between males and females at the national level throughout the available published literature (i.e., minimal differences in coverage between men and women). However, it is unclear at this stage whether that finding holds at a sub-national level.

Act to End NTDs | West's analysis (Khan et al. 2019) of the 11 countries' training data revealed that the role of women in human resources for health for NTDs, whether as community drug distributors (CDDs), M&E staff, school-based distributors, lab technicians or supervisors, was (in most cases) significantly lower than that played by men, with percentages of women trained for these roles often hovering in the teens.

Phase one analysis revealed gaps in data and literature that will need to be explored in phase two; such gaps include the lack of accessible data disaggregated by sex, age, disability, and pregnancy status.

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<sup>18</sup> The NTDs covered by the program include trachoma, lymphatic filariasis, onchocerciasis, schistosomiasis, and three soil transmitted helminths (hookworm, roundworm and whipworm).

<sup>19</sup> The countries are Benin, Burkina Faso, Cameroon, Cote D'Ivoire, Ghana, Guinea, Mali, Niger, Senegal, Sierra Leone, and Togo.



While sex-disaggregated MDA program coverage data is aggregated at the national level, the sex-disaggregated data from sub-national (district/peripheral) levels was not reported up to the national level and therefore not available for analysis at this time, although it might be possible to obtain this information for specific countries during the next phase of the analysis. Age, disability and pregnancy status data are not available at any level, however. These data gaps make it difficult to identify who and where groups are being left behind at the more granular level. Overall, the literature was thin on the relationship between gender and NTDs with no literature or any real discussion about the most important of gender domains, that of power: who has it, who doesn't and how that plays out at the various levels of the socio-ecological model from policies, institutions, communities and, most importantly, at the household level to impact who gets sick, who doesn't, who accesses services and what impacts illnesses have. Finally, there was no literature on the ways that gender might intersect with other vulnerabilities such as disability, socio-economic status, education, religion, ethnicity, etc.

Also limited was the literature or guidance available on how to integrate gender throughout NTD programming, including: effective social and behavior change communication (SBCC) approaches for changing harmful gender norms and promoting positive ones; how to engage and track pregnant women; programming on the intersection of HIV and NTDs, particularly female genital schistosomiasis (SCH); and, increasing women's participation as human resources for health in NTD programming in ways that are empowering rather than exploitative.

With these gaps in mind, the next step is to finalize the selection of countries for the phase two qualitative data collection, with an emphasis on Muslim/Christian populations; countries that pay community drug distributors (CDDs) as well as those that don't; countries with high rates of female CDDs as well as those with lower rates; and at least one country with a generalized HIV epidemic to look into HIV and schistosomiasis coinfection. Once the countries have been selected, the program will further analyze available quantitative data to identify district level differences in coverage or outcomes in order to select contrasting sites for focus group discussions.

Within these more in-depth country studies, we will focus on

- Additional information from national and subnational gender and empowerment indicators (if they exist) and study how they relate to NTD elimination and control efforts;
- How NTDs are, or could be, integrated into other health interventions that target diseases such as AIDS, cervical cancer and other sexually transmitted infections;
- Identify any existing district level data to identify gaps in coverage or outcomes and potential gender related considerations;
- How SBCC programming is targeting and reaching vulnerable populations;
- The impact of disability on NTD coverage;
- The differential access to MDA through school or community-based campaigns; and
- How the program can improve outcomes through additional focus on gender and social inclusion as well as how the program itself can increase equity and empowerment of women and girls and other vulnerable populations.

## **Introduction/Background**

### Program Background

Act to End NTDs | West is a five-year (2018-2023), \$200 million program funded by USAID to control or eliminate five NTDs in Sub-Saharan West Africa.<sup>20</sup> The FHI 360-led consortium includes partners: Helen Keller International, HDI, Deloitte Consulting, World Vision, AmeriCares, and AIM Initiative.

Act to End NTDs | West expands and deepens USAID's efforts to control or eliminate trachoma, lymphatic filariasis (LF), onchocerciasis, schistosomiasis and soil-transmitted helminthiasis (STH) in 11 West African countries—Benin, Burkina Faso, Cameroon, Cote d'Ivoire, Ghana, Guinea, Mali, Niger, Senegal, Sierra Leone, and Togo. The new program supports disease-endemic countries to eliminate and/or control NTDs using preventive chemotherapy (PC) through proven, cost-effective public health interventions.

Act to End NTDs | West will build on the achievements of the END in Africa and ENVISION projects in West Africa in their efforts to eliminate lymphatic filariasis (LF) and trachoma as public health problems, and the elimination of onchocerciasis in selected countries. The new program aims to make NTD programs capable of sustaining treatment for long-term control programs for SCH, STH and onchocerciasis (the latter in selected countries) and to mainstream NTD programs into the national health system.

As a way to ensure Act to End NTDs | West is equitably addressing the needs of men, women, boys and girls with NTD control and elimination activities, the program team has engaged two Gender Advisors to conduct a gender analysis and to develop a gender strategy for the program, to be completed by the end of fiscal year 2019.

#### Gender Concepts and USG Gender Imperatives

USAID has long supported gender equity in development activities and deepened their commitment in 2012 with the adoption of the *Gender Equality and Female Empowerment Policy*, which stated that all USAID investments across all sectors and fields are aimed at the achievement of three overarching outcomes: reducing gender disparities in access to all types of assets; reducing and mitigating gender-based violence (GBV); and increasing women and girls' empowerment. The policy further noted the importance of understanding intersectionality – multiple layers of marginalization that some individuals face, including poverty, ethnicity, and disability. The policy is operationalized at the program level by translating these three outcomes into specific results with associated targets and indicators.

According to USAID's operational policy on integrating gender equality and female empowerment (Automated Directives System (ADS) 205), the means for translating these outcomes into results is via a gender analysis (see Key Definitions box). The Notice of Funding Opportunity for Act to End NTDs | West

#### **Key Definitions:**

**Gender** refers to a culturally defined set of economic, social, and political roles, responsibilities, rights, entitlements and obligations associated with being female and male, as well as the relationships between and among females and males. The definition and expectations of what it means to be a male or female varies across cultures and over time.\*

**Gender Analysis** is an analytic tool used to identify, understand and explain gaps between males and females that exist in households, communities and countries, and to identify the relevance of gender norms and power relations in a specific context.†

\* Interagency Gender Working Group (IGWG).

<http://www.igwg.org/training/DevelopingSharedVocabulary/DefiningGenderRelatedTerms.aspx>

† ADS Chapter 205, USAID, July 2013

<sup>20</sup> The diseases slated for elimination are trachoma, lymphatic filariasis and onchocerciasis (in selected countries), while the disease slated for control are schistosomiasis, soil transmitted helminths and onchocerciasis (in selected countries)

(Number: 7200AA18RFA00010) states that: “The Recipient(s) will be asked to conduct a gender analysis, as necessary, after the signing of the Agreement. This analysis will inform a subsequent Gender Strategy, which will be developed in collaboration with the USAID management team and finalized within six months of signing the Agreement. The Gender Strategy will inform the program’s technical approach as it relates to gender throughout the life of program and should be reflected as relevant in annual workplans, reporting, and activity monitoring, evaluation and learning (MEL) plan indicators.” This document represents Phase I of the Act to End NTDs | West gender analysis and strategy study; Phase 2 will entail the qualitative field work and the articulation of a gender strategy for the program.

## **Gender Analysis Objectives and Methodology**

The objectives of the gender analysis of Act to End NTDs | West are to identify:

- How NTDs might differentially impact women and men, girls and boys, recognizing intersectionality;
- How gender norms and roles, power dynamics, including social exclusion of people with disabilities, might affect the attainment of program results; and
- How program activities could advance gender equality and social inclusion and promote sustainable health outcomes.

The gender analysis will use standard social science quantitative and qualitative data analysis methods following usual gender assessment practices. Data are collected from three sources: a review of published and grey literature (during Phase I), a quantitative analysis of sex-disaggregated NTD data using secondary sources (during both Phases I and II), and a qualitative data gathering through key informant interviews and focus group discussions (during Phase II).

Generally speaking, a quantitative analysis can help to identify gaps between men and women regarding NTD status and access to care as well as to generate evidence on the relationship between access and use of NTD services and gender inequality. A qualitative analysis can help to better explain how gender norms within given contexts impact men’s and women’s, as well as boys’ and girls’ abilities to adopt healthy practices in relation to NTDs, use NTD services, participate in health programming as well as provide opportunities to engage individuals in identifying solutions

The gender analysis has been divided into phases. This Phase I interim report is based on a literature review and an initial quantitative analysis.

Included in the literature review are published and unpublished literature on gender and NTDs, current program and previous programs’ reports, and reports and materials produced by donors and implementing organizations. The team searched for materials on each NTD, for each Act to End NTDs | West country, as well as any relevant gender materials.

This phase also draws on the quantitative analysis documented in *Gender Analysis of ACT to End NTDs | WEST Program using MDA Coverage and NTD Training Data* by Khan et al., 2019 and *Gender equity in mass drug administration for neglected tropical diseases: data from 16 countries* by Cohn et al., 2019 as well as other sources.

In addition to contributing to the overall gender analysis, this interim report will serve to inform Phase 2 fieldwork in terms of identifying the gaps, opportunities and potential recommendations that should be further explored through qualitative data collection during fieldwork.

## Findings

The program currently has sex disaggregated data for programmatic aspects including MDA treatment data and CDD training data, which is currently being analyzed. Program data on prevalence for each NTD and country, disaggregated by sex should be available for Phase II of this gender analysis. For Phase I, we will limit the analysis to results using data on treatment coverage.

Generally speaking, other than trachoma, where women are between 2 and 4 times more likely to be infected, the rates of infection for NTDs are generally comparable across sexes (WHO, 2013). While the sexes may experience similar infection rates, women and girls face additional health impacts as a result of NTD infection. These include increased anemia during pregnancy brought on by helminth infection (Aderoba et al., 2015) or genital schistosomiasis, which also increases vulnerability to HIV infection (Mbabazi et al., 2011).

### Differential Health Impacts of NTDs

#### *Female genital schistosomiasis (FGS) and HIV*

Evidence from many types of studies supports four links between urogenital schistosomiasis and HIV infection: 1) schistosomiasis causes tissue damage and inflammation of the female genitals and genital tract increasing a woman or girl's susceptibility to HIV infection; 2) genital schistosomiasis in HIV positive women and men increases their viral shedding, making it easier to transmit HIV to their sexual partners; 3) chronic schistosomiasis alters global immune function, increasing susceptibility to HIV infection for both sexes; and 4) schistosomiasis infection speeds up the progression of HIV by increasing the viral load. Since many girls experience schistosomal lesions in childhood, intervening before and during the teenage years may decrease the risk of HIV as well as reduce morbidity associated with genital schistosomiasis in adulthood (Mbabazi et al., 2011). The latter is especially important since women and girls are disproportionately impacted by HIV, including being infected at earlier ages. In sub-Saharan Africa where schistosomiasis is prevalent, roughly 5,500 young women and adolescent girls are infected with HIV every week (unpublished WHO/UNAIDS study). AIDS-related illnesses remain the leading cause of death for women aged 30-49, and the third leading cause of death for women aged 15-29 (UNAIDS, 2017). In some areas the gender discrepancy is even more pronounced; in East and Southern Africa, where young women aged 15-24 years become infected with HIV five to seven years earlier than their male peers (Dellar et al., 2015). All of the gender inequalities and intersectionalities – poverty, disability, power imbalances, and GBV - which increase risk for HIV and hamper access to services also extend to NTDs (UNAIDS, 2016). As an example, in Senegal, Niger, Burkina Faso, Côte d'Ivoire and Cameroon, 80% of married 15 to 19-year old women do not have the final say on their own healthcare (UNAIDS, 2014).

Recognizing the co-morbidities, the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) met during the 22nd International AIDS Conference in July 2018. Discussions focused on ways to combine screening and testing for HIV, sexually-transmitted infections (STIs) and cervical cancer with that for female genital schistosomiasis (FGS) to improve detection and treatment. They also called for schistosomiasis treatment to be extended to adults, prioritized in

national programs and included in interventions that target diseases such as AIDS, cervical cancer and other sexually transmitted infections (WHO, 2018).

#### *Schistosomiasis, hookworm and maternal Health*

Schistosomiasis affects both maternal and infant morbidity and mortality. In Africa, an estimated 10 million pregnant women are infected with schistosomiasis, and half of those will go on to develop severe anemia and associated complications, including low birth weight infants and increased maternal and infant mortality (Friedman et al., 2007). Schistosomiasis can also be transmitted via the placenta resulting in congenital infection of newborns. Pregnant women infected with schistosomiasis may also experience higher rates of spontaneous abortions and ectopic pregnancies (Nour et al., 2010).

Women infected with schistosomiasis or hookworm (one of three STHs, the other two being roundworm and whipworm) are more vulnerable to severe anemia (Hotez et al., 2014; Rilkoff et al., 2013), which in turn causes an estimated 20% of maternal deaths in Africa (Kagu et al., 2007); approximately 7% of these anemia deaths are caused by hookworm infection (Hotez et al., 2009). The estimated 44 million pregnant women infected with hookworm globally includes up to one-third of all pregnant women in sub-Saharan Africa (Brooker et al., 2008).

In addition to anemia and poor maternal and infant outcomes, both hookworm and schistosomiasis contribute to infertility. Hookworm related anemia is a form of iron deficiency anemia caused by gastrointestinal blood loss as a result of the feeding activity of intestinal hookworms (WHO, 1996). Hookworm related anemia causes amenorrhea, and genitourinary schistosomiasis leads to inflammation of the uterus, fallopian tubes, and ovaries (Hotez et al., 2009). Up to 3.6% of ectopic pregnancies and 41% of infertility cases are attributed to female genital schistosomiasis in endemic areas (Kjetland et al., 2010).

#### Differential social impacts of NTDs

The social consequences of NTD infections impact men and women differently and may disproportionately impact women, particularly when NTD infections negatively affect socially ascribed assets and attributes for femininity such as beauty, marriage, motherhood and childcare.

#### *Infertility*

In some settings women who do not demonstrate fertility may be divorced, set aside for second wives or suffer verbal and physical abuse. Infertility has adverse psychosocial and economic implications for affected women/families in most developing countries. In sub-Saharan Africa, more than a third of women aged 25–49 suffer from secondary infertility or the failure to conceive after an initial first pregnancy (WHO, 2004). Infertile women may suffer discrimination, stigma and ostracism from their partners, their families and the broader community because of a perceived inability to continue the family line or contribute to the economic well-being of the community (WHO, 2010).

#### *Physical Disfigurement and stigma*

Both men and women infected with NTDs can experience stigma and discrimination due to disfigurement and disability, leading to poor mental health and reduced quality of life (Litt et al., 2012). Those who experience stigma and discrimination may internalize feelings of shame or guilt - “self-stigma” - or withdraw from community life to avoid future anticipated stigma. In addition to self and anticipated stigma, individuals experience stigma and discrimination from others in their families,

communities, schools and even healthcare settings. Just as with HIV, stigma can hamper NTD diagnosis and treatment, particularly when perpetrated by health care workers (Hofstra et al., 2016).

Lymphatic filariasis (LF) is the second leading cause of permanent disability worldwide (CDC, 2016). People with the disease can suffer from lymphedema and elephantiasis and, in men, hydrocele. Lymphedema occurs more frequently in women than in men and often involves the breasts and genitals (Hotez et al., 2009). Being female, young, having genitals affected, being poor or having advanced infection all are associated with higher levels of stigma (Hofstra et al., 2016). The same systematic review on NTDs and social stigma (Hofstra et al., 2016) found fourteen studies that cited inability to fulfil a certain gender role as leading to stigmatization, where that inability includes reproducing, having sexual relations and performing household chores. Hofstra et al. also noted that while higher levels of stigma were associated with being female, men also experience stigma due to hydrocele and the inability to fulfil gender roles. Other studies have found that women with LF-associated lymphedema or elephantiasis or disfigurement from onchocerca skin disease (one of the morbidities associated with onchocerciasis) experience social ostracization resulting in fewer opportunities for marriage (Krishna Kumari et al., 2010; Hotez et al., 2009; Rilkoff et al., 2013; Vlassoff et al., 2000).

In addition to limiting marriage opportunities, stigma and discrimination related to disability and disfigurement resulting from NTD infection limits women and girls' employment opportunities further impacting their economic wellbeing and independence (Hotez et al., 2009).

### *Blindness*

While trachoma is slated for elimination as a public health problem by 2020, millions remain at risk in endemic areas. An estimated 157.7 million people living in trachoma-endemic areas are at risk (WHO, 2019). Trachoma is the one NTD where infection rates are disproportionate, with girls and women two to four times more likely to be infected and twice as likely as men and boys to develop trichiasis (Cromwell et al., 2009). Women account for 80% of Disability Adjusted Life Years (DALY) lost due to trachomatous blindness and visual impairment (Frick et al., 2003). Gender role factors likely explain these differences in infection rather than biology (Doyal et al., 2018). See below for more on vulnerability related to gender roles.

Trichiasis has a significant negative impact on affected women's quality of life, including experiencing stigma and discrimination (Hofstra et al., 2016). Trichiasis affects women's ability to marry, enjoy a social life, have good relationships, be employed, or participate in religious obligations (Palmer et al., 2014). Affected women experience self-stigma through internalized feelings of shame while perpetrators of external stigma justify their behavior by attributing it to the affected person's perceived contagiousness, inability to fulfil gender roles and being a social and financial burden to the family. For all of these reasons, women experience a precipitous decline in their independence (Palmer et al., 2014). More recent studies have found similar impacts of onchocerciasis and trachoma blindness or vision impairment on women's employment, mobility and social lives (Bangert et al., 2017).

### Vulnerability related to gender roles

As noted in the definitions, gender refers to culturally defined economic, political and social roles. Caroline Moser, a leading social anthropologist and policy analyst, developed a gender planning and analysis framework which introduced the concept of the "triple roles" of women: productive, reproductive and community (Moser et al., 1993). Productive roles include any work done by both men

and women for pay in cash or in-kind and includes both market and subsistence production. Reproductive roles include childbearing and rearing responsibilities as well as domestic tasks done by women for the care and maintenance of the household and family. Community roles encompass all activities for the maintenance of the community such as water, health care and education. This is usually voluntary unpaid work, undertaken in 'free' time. Community Drug Distributors (CDDs) performing unpaid drug distribution and community education activities, as discussed below, would be an example of those taking on a community role. While men and women play all three roles, men generally focus on a single role (usually productive) at a time, while women play multiple roles simultaneously, balancing competing demands (ILO, 1988).

Women's and men's, as well as boys' and girls' vulnerability to NTD infection is often related to their productive, reproductive and community gender roles. For example, in endemic countries incidence of inflammatory trachoma is highest among children under five, and therefore, women, who spend more time with young children in their reproductive role as caregivers, are exposed to repeated infection leading to increased incidence of blindness (Doyal et al., 2018; Courtright et al., 2012). Trachomatous trichiasis (TT) – in-turned eyelashes from repeated infection with *Chlamydia trachomatis* – can be cured through surgery but uptake of TT surgery remains low in part due to gender role expectations. Women report that they cannot access the surgery, even when the surgery and transportation is free, due to gender role expectations regarding childcare, work responsibilities and the need for someone to accompany them (Bickley RJ, et al., 2017).

Activities such as washing clothes and fetching water may expose women and girls to increased risks of developing schistosomiasis in endemic areas (Adenowo et al., 2015; Bangert et al., 2017; Cohn et al., 2018). This is particularly true since two-thirds of water collection is performed by women and girls (WHO, 2009). However as seen below, in some instances, men and boys may be at increased risk due to occupational exposure.

As with virtually all illnesses, women also bear a disproportionate burden for caring for those infected by NTDs in their family and communities whether in caring for them at home or in seeking treatment outside of the home (Theiler, 1998). One small study in Malawi examined the role of caregivers for those who experience painful, disabling acute dermatolymphangioadenitis (ADLA) attacks caused by LF. The study found that the majority of caregivers are female, with the largest percentage being daughters followed by wives, but noted the dearth of research on the impact of caregiving on women and girls, especially with regards to education and employment (Martindale et al., 2017).

Men and boys are most often put at risk when carrying out their productive roles. This is true for schistosomiasis where social and occupational activities such as fishing and farming put men at increased risk of contracting the disease (Rilkoff et al., 2013; Mitra et al., 2017; Adenowo et al., 2015). Male school children had a higher infection level of schistosomiasis than girls in Ghanaian communities along irrigation canals. While both boys and girls were exposed to the water, significantly more males than females swam in the canals, washed their clothes there and also worked on rice farms. More females reported washing dishes in the canals, but this activity held less exposure to infection (Anto et al., 2013). Another study found an increased risk for LF among males who hunt or fish, particularly at night (Chesnais et al., 2014).

#### Impact of deworming on work and school: economic consequences

Studies have shown long-term impacts of school de-worming programs (in relation to STH), including differing impacts for males and females. One study conducted ten years after school de-worming, found that the boys stayed in primary school longer, worked more hours per week, spent more time in nonagricultural self-employment, were more likely to hold manufacturing jobs, and missed one fewer meal per week than boys who were not part of school deworming. Girls who attended schools that conducted de-worming were 25% more likely to have gone to secondary school than girls who were not part of school de-worming—cutting the gender gap in access to secondary school in half. Other impacts on the women include that they had changed from traditional agriculture into cash crops and nonagricultural self-employment (Baird et al., 2016). These findings are in line with evidence demonstrating that, in low-income settings, investments in health programs yield larger educational impacts for females, who move into more skill-intensive occupations, while reinforcing men’s dominance in work that requires raw labor, leading to an increase in wage disparity in “brawn” based economies (Pitt et al., 2014).

A prospective double-blind, randomized effectiveness trial among women smallholder farmers in the Democratic Republic of Congo sought to answer the question of whether treatment with albendazole for STH would affect their work capacity. The women farmers were allocated to four different groups: hookworm positive plus placebo, hookworm positive plus treatment, hookworm negative plus placebo, and hookworm negative plus treatment. Each group was given a step test as a proxy metric for work capacity at the start and end of the study. Treatment with albendazole was associated with improved aerobic work capacity post-treatment for the hookworm positive plus treatment group (Salmon et al., 2018).

Despite on-going debate about the interpretation and methodologies of these studies (Jullien et al., 2016) they point to mass drug administration for STH as an efficient and cost-effective means of improving not only boys and men’s but also women and girls’ health, economic opportunities and empowerment in resource poor environments (Hotez et al., 2018).

When the prevalence or consequences of infection fall more heavily on women, equal MDA coverage may not fully remediate differential harm, particularly at lower levels of coverage, (Cohn et al., 2018) and additional programming or resources must be allocated to equitably address gender differences in harm.

#### Gender differences in community-based MDA coverage rates

Across various countries implementing mass drug administration programming for NTDs, MDA program coverage has been largely equal at the national-level (i.e., minimal differences in coverage between men and women), but it is less clear to what degree this holds at sub-national and community levels in most cases (Rubin Means, 2016). While the literature has postulated various ways women might face barriers to being reached through mass drug administration campaigns (such as conflicting household responsibilities, lack of decision-making power within the home, social norms not permitting women to accept PCs from male CDDs, and pregnancy or breastfeeding status). In our review of the literature, we found mixed results depending on disease, country, and year. A few studies have suggested that men may be less likely to participate in MDAs, in part due to lack of access when work or occupational travel draws them away from MDA sites (Cohn et al., 2018), but the findings were not necessarily generalizable across NTD programs and countries.



Pregnant women are sometimes formally or informally excluded from certain types of MDAs for which they are eligible under WHO guidelines. WHO encourages inclusion of pregnant and lactating women in schistosomiasis MDA, yet in practice many national programs still do not target them for treatment, either because of perceived risks or because schistosomiasis MDAs are often targeted at school-age children and/or use school-based platforms to administer the drugs (i.e., for the latter, the targeting strategy excludes pregnant and lactating women by design). Lack of knowledge among CDDs regarding safety of MDA for pregnant and lactating women can result in the exclusion of women eligible for treatment (Rilkoff et al., 2013; Hussain et al., 2014).

In terms of data availability, an analysis completed by Cohn et al., 2019, from 16 ENVISION and End in Africa implementation countries (Benin, Burkina Faso, Ethiopia, Ghana, Guinea, Haiti, Indonesia, Mozambique, Nepal, Niger, Nigeria, Senegal, Sierra Leone, Tanzania, Togo, and Uganda) between 2012-2016, found that 90% of districts from these 16 countries were collecting sex disaggregated coverage data in 2016, up from 32% in 2012; and 11 out of the 16 countries reported sex disaggregated data from all districts in 2016 (Cohn et al., 2019).

According to the 2016 district level data from the Cohn et al. study, the median MDA coverage for all targeted diseases was slightly higher for females than males when aggregated across all countries (ranging from 9.4% higher for LF MDA to 2.3% higher for trachoma MDA). When analyzed by country, district-level MDA coverage was higher among females in all countries except Haiti and Mozambique. Coverage among females was more than 10% higher in Nigeria, and more than 5% higher in Burkina Faso, Senegal, Niger, and Tanzania (Cohn et al., 2019).

Another aspect to consider when thinking about equity in MDA coverage, is that in most settings distributors are supposed to directly observe treatment, in effect meaning that reported treatment coverage and actual ingestion of the drug essentially should be identical. In some countries, however, treatment is provided to households, but ingestion is not directly observed. In such settings, prior research has found that gender-related power dynamics can increase the risk that women who receive drugs without directly observed treatment by CDDs may not in fact ingest the drugs due to a variety of factors, including lack of knowledge on the benefits of MDA, low perception of risk, distrust, or medication being given to another family member (Cohn et al., 2019).

Disabled individuals may have additional barriers accessing fixed distribution points, another potential cause of inequitable treatment coverage. For example, in one study on MDAs from Nigeria, people living with a disability may be excluded from MDAs because of a lack of understanding among CDDs on how to treat people living with disabilities, particularly when these people are unable to stand or are perceived to be sick due to their disability (Theobald et al., 2017; Hotez et al., 2017). Additionally, this study found that the measuring sticks used for determining treatment dosage by height are not able to correctly measure persons with physical disabilities such as those using wheelchairs, and there is no guidance provided to CDDs on how to adapt this measurement tool for persons with disabilities (WHO, 2017).

#### Breakdown of Community Drug Distributors and other MDA staff by sex and effect on MDA coverage

Community Drug Distributors (CDDs) are well-placed to understand and address the gender-related dynamics at the household and community level as they relate to MDAs. They can act as agents for change with appropriate training and supportive supervision, and they can flag gender-related issues for program staff. This increased responsibility can lead to greater recognition and support both career and social advancement, which is particularly helpful for female CDDs (Theobald et al., 2017).

Despite examples demonstrating that female CDDs may demonstrate higher job performance, the majority of drug distributors and other staff contributing to MDA in many countries are male (Katabarwa, et al., 2002; Weldegebreal et al., 2016; Massa et al., 2009; Clemmons et al., 2002). Out of 14 studies reporting sex-disaggregated data on CDDs, only two documented a greater proportion of female compared to male drug distributors (Omedo et al., 2012; Lynch et al., 2003). Local cultural and political structures, and safety concerns may influence the selection against female drug distributors and, in some cases, the extent of their participation (Brieger et al., 2002; Masa et al., 2009; Omedo et al., 2012). Research from the WHO *Integrating a Gender, Equity, and Human Rights Focus into National Programming on Preventative Chemotherapy and Transmission Control for NTDs* project from 2016-2019 found that the selection of CDDs was mostly determined by men, who reported not selecting women due to an opinion that women were too weak to take on the role (WHO, 2017).

According to the data available from the End in Africa and ENVISION projects for the 11 implementation countries between 2014-2017 (Khan et al, 2019), MDA training rates for three categories of staff, CDDs, other MDA staff, and trainers/supervisors, were almost universally much higher for men than women.

The low percentage of female CDDs trained was particularly stark in Benin (roughly 20% from 2015-2017); Burkina Faso (below 30% all four years); Guinea (30% on average); Mali (26% on average); Niger (21% on average); Sierra Leone (30% on average); and Togo (21% on average). Ghana was the exception, in which a higher percentage of female CDDs were trained for three out of the four years analyzed. The reasons for the high percentage of female CDDs in Ghana warrants further exploration during the qualitative field work – to see why, unlike other countries, there were no barriers to hiring female CDDs in this country.<sup>21</sup>

For other MDA staff, including M&E staff, school-based distributors, and lab technicians, the average rates of females trained were significantly lower than that for males. The most dramatic differences were seen in Burkina Faso where the average percentage of women trained was 15%; Cote d'Ivoire (19% in 2016 and only 2.8% in 2017); Ghana where no women were trained for these roles in 2015-2016 but 66% were trained in 2017; Guinea (average of 15%); Mali (average of 12%); and Togo (average of 12%). The only exception was Sierra Leone, where females trained were dramatically higher than men for all four years (average of 70%). Again, the positive results in Sierra Leone warrant further investigation during the qualitative field work.<sup>22</sup>

For trainers/supervisors, Ghana, on average, trained slightly more women than men, but each of the other countries trained a much higher proportion of men than women for these roles. The rates of women trained between 2014-2017 for these roles were lowest in Burkina Faso (average of 19%); Cote d'Ivoire (average of 13%); Guinea (average of 25%); Mali (average of 14%); Niger (average of 31%); and Togo (average of 13%).

While useful, the study by Khan et al., 2019 only looked at the breakdown of CDDs trained (as this was the only data available) and did not consider sex-disaggregated data on CDDs actually conducting mass drug administration, attrition rates, or experiences and effectiveness of the CDDs. Therefore, it is difficult to clearly demonstrate the impact of the hiring inequities on the MDAs themselves, but we can

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<sup>21</sup> Ghana is likely to be one of the countries visited during the qualitative field work.

<sup>22</sup> Sierra Leone is also likely to be one of the countries visited during the qualitative field work.

determine that aside from Ghana (for CDDs and supervisors), all program countries are training and engaging women at proportions far below equitable levels.

Some evidence suggests that MDA programs delivered by female CDDs can achieve equal or greater coverage, with less participant attrition compared to male counterparts (Vouking et al., 2015; Jenson et al., 2014; Brieger et al., 2002; Katabarwa et al., 2002). Community members often reported female CDDs as more committed, persuasive, and patient than men (Vouking et al., 2015), and some studies have identified underutilization of female CDDs as one reason for limited effectiveness of ivermectin distribution in the treatment of onchocerciasis (Vouking et al., 2015).

In one study from Nigeria and Cameroon, 81% of people in villages with female CDDs were reached with ivermectin as opposed to 78% where CDDs were male, indicating slightly higher MDA coverage rates for women (Brieger et al., 2002). One study in Uganda similarly found that female CDDs outperformed male CDDs (Krentel et al., 2017; Katabarwa et al., 2005). Another study in Uganda found that social hierarchies impacted female CDDs' effectiveness, as younger women were not able to insist that older men take the pills in their presence (Krentel et al., 2017; Parker et al., 2011). According to the end of program report for End NTDs in Africa, recruiting women as CDDs was an effective strategy in Niger, increasing coverage in many areas, because women can enter households whereas men are not always allowed to do so (FHI 360, 2018).

#### *Impact of CDD role on women's lives*

Ensuring that women are selected, trained and supported to act as CDDs as part of MDA programs has the potential to elevate the social status of women and provide them rewarding and valuable skills and experience (Mutalemwa et al., 2009). However, given that in most contexts, women are responsible for the vast majority of domestic duties, the additional responsibility of drug distribution may overburden female CDDs (Katabarwa et al., 2001; Omedo et al., 2012).

In some contexts, it is very acceptable for women to act as CDDs; for example, in Uganda men were found to be overwhelmingly supportive of their wives acting as CDDs (Katabarwa et al., 2001). In other societies, it is considered inappropriate for women to travel outside the home or to travel from house to house. In one study from Kenya, some female CDDs reported physical or emotional abuse from their husbands for coming home late after distributing drugs, and some female CDDs had to justify their work as CDDs to their husbands (Omedo et al., 2012).

#### *Paid versus unpaid CDDs*

Of the 11 countries Act to End NTDs | West is working in, only Sierra Leone and Togo pay their CDDs. While relying on unpaid volunteers to implement MDAs can be a challenge across the board, this can be particularly harmful for female CDDs, unintentionally reinforcing norms that encourage women to participate in uncompensated labor (Arakaki et al., 2016). Additionally, since women and girls most often do the majority of housework and caretaking, both unpaid labor and the devaluing of female CDDs' time reinforces gender stereotypes that caretaking is a women's role and does not merit financial remuneration (Arakaki et al., 2016). In the context of the larger health system, paid positions in the health sector are often predominantly held by men. From the information available in the final project report from End in Africa, women were trained for paid positions at much lower rates than men, meaning that while women may be given opportunities to participate in the volunteer cadres of health systems in many sub-Saharan African countries, they are often excluded from the more respected and financially invaluable roles.

## Knowledge Gaps

Uniting to Combat NTDs held a meeting in July 2016 with a focus on women and girls. Prior to that meeting, a landscape review and key informant interviews were conducted to inform a gender analysis on NTDs. As part of this effort, meeting participants were asked to identify what they perceived to be the most important gaps in knowledge or information in relation to gender. They identified the following:

- Lack of available and accessible high-quality sex- and age disaggregated data
- Guidance on how to include gender considerations during program design and delivery, which could have implications in the way programs are monitored, and data is collected
- Guidance on reaching and treating pregnant women through MDAs
- A need for a deeper understanding of the interaction between HIV and NTDs, particularly female genital schistosomiasis (Arakaki et al., 2016).

Theobald et al., built on the July 2016 Neglected Tropical Diseases: Women and Girls in Focus meeting that brought together donors, researchers, policy makers and practitioners from different contexts to conduct an analysis of how well NTD programming had mainstreamed gender over the last 20 years and found that the majority of NTD programs were actually “gender blind” meaning they do not take gender into consideration in design, delivery or evaluation.

This review thus far echoes those findings in terms of gaps identified, namely:

### Gaps in Evidence/Literature:

- Overall, the team looked for any literature on NTDs and gender. It was not possible to find much literature on gender for each disease and/or country covered by the Act to End NTDs | West program, with some program countries not being mentioned in any of the literature on gender and NTDs.
- Without sex, age, and disability disaggregated data available at the sub national level it is hard to determine and target the groups that might be being missed.
- While there was some literature on how men’s and women’s different gender roles affect their vulnerability to NTDs and a little on how experience of NTDs impact those gender roles, there was less available on certain aspects of gender roles such as impact on women and girls as caregivers when someone in the family is ill or disabled due to NTDs.
- While there was some literature available on how NTDs cause disability, and the different impacts of those disabilities on men and women, there was little about whether or not the disabled were accessing programming and health services. So, while the literature reported on how NTDs cause disabilities they did not report on how a disability impacts being able to participate in programming.
- Most literature, even if it did look at how men’s and women’s experiences might be different, did not go deeper into the issue of intersectionality to include other factors such as poverty, disability, education, etc.
- Related to the two points above, there was no literature or any real discussion about the most important of gender domains – that of power – who has it, who doesn’t and how that plays out at the various levels of the socio-ecological model. This includes the levels of policies, institutions, communities and, most importantly, at the household level to see who gets sick, who doesn’t, who accesses services and what impacts each illness has.

- Not much information was available to be able to determine whether being engaged as a CDD is particularly exploitative or empowering for women. Does it add to a woman's burden of unpaid labor or does it increase her stature in the community and her household, and open a pathway to employment? Are women's CDD experiences different from those of men?
- There was nothing in the literature about NTDs and GBV – in relation to participating in services or serving as a CDD, in relation to children being infected, or in association to women's and children's disability and disfigurement.
- There was no information on programming to address the intersection of HIV and NTDs, particularly female genital schistosomiasis.
- There was no literature on effective social and behavior change communication (SBCC) strategies, approaches or materials to address NTD risks and treatment from a gender perspective.
- Along with the legal and educational systems, religion plays an important role in setting and maintaining gender norms and roles. The team found no literature which discussed religion's impact on expectations for men and women in relation to NTDs.

#### Gaps in Data:

- While there were sex-disaggregated MDA program coverage data available at the national level, the data were not age disaggregated and there were gaps at the sub-national (district/peripheral) levels.
- Additionally, there were no data on MDA program coverage or CDD engagement of the disabled by disability status
- Prevalence by disease, country and sex was not readily available.
- Data for MDA was not available by delivery method (school-based versus community-based MDA) disaggregated by age and sex.
- No data on pregnancy status of those reached in programming.

### Opportunities

Despite the various challenges noted above, there are opportunities to gather more data and fill in some of the gaps in information on gender-related considerations for successful NTD programming in West Africa. Ahead of the planned qualitative data collection as part of this gender analysis, we expect a report in the next couple of months, produced by the Act to End NTDs | West program, which will provide both coverage and prevalence data, disaggregated by sex, for each targeted disease from each of the Act to End NTDs West program countries.

Additionally, WHO will be releasing a guidance document in 2019 on how to review and evaluate national NTD programs with a focus on reaching the most marginalized, and WHO has also released a call for papers on gender and NTDs to improve the evidence base in this field.

### Discussion

Overall, the literature available on NTDs and gender was sparse, particularly when considering each NTD separately in each of the 11 countries. The available literature can provide generalizable evidence on biology including vulnerability to and biological experience of NTDs since the anatomy of males and females is the same from context to context. With regards to biology, women are more impacted as compared to men in their experience of trachoma and in the biological impacts of schistosomiasis and

hookworm infection, particularly with regards to their reproductive role as mothers. Both infections impact maternal and infant morbidity and mortality. Given pregnant women's increased vulnerabilities, lack of data on their access to, and use of, NTD programming, including MDAs, is problematic.

Evidence exists to show a fourfold relationship between urogenital schistosomiasis and HIV and has led the WHO and UNAIDS to call for more integrated programming such as combined screening and testing for HIV, sexually-transmitted infections (STIs), cervical cancer and female genital schistosomiasis (FGS) for women and girls in order to improve prevention, detection and treatment. They also called for schistosomiasis treatment to be extended to adults, prioritized in national programs and included in interventions that target diseases such as AIDS, cervical cancer, and other STIs (WHO, 2018). However, there was no literature found on best practices for how to better integrate NTDs and HIV programming (at least in NTD endemic districts where treatment for NTDs occurs). It is possible to look to other integration efforts such as the integration of GBV prevention, screening and clinical services with HIV and STI programming and services. This will be particularly urgent in the program's target countries which have higher HIV prevalence.

While anatomical and biological vulnerabilities and impacts remain the same across all countries, gender norms and expectations vary between and within countries depending on ethnicity, religion, customary law, socio-economic status, etc. The literature contains examples of how gender roles can increase exposure and vulnerability to NTDs but only one of those roles – mothers caring for children with inflammatory trachoma - holds across settings. To a slightly lesser degree, women's and girls' exposure to schistosomiasis in endemic areas, through their roles in washing clothes and fetching water, is roughly the same across countries in that two-thirds of water collection is performed by women and girls (WHO, 2009). But other findings in the literature regarding exposure due to tasks such as fishing or farming would need to be explored in the local context, given that those roles can be taken on by either males or females. Such an exploration of roles could be overlaid with sex and age disaggregated data on prevalence for each country context to provide more context and would be more informative still at subnational levels given that gender norms and expectations can vary within countries.

One area where biological vulnerability and gender norms overlap was in lymphedema caused by LF which is more common in women and has significant impacts in terms of stigma and discrimination. While men experience stigma as well due to hydrocele and inability to fulfil gender roles, the impacts of disfigurement appear to impact women more severely including impacting women's mobility, employment and independence – all key to women's empowerment. The literature on stigma – experienced, anticipated and self-stigma – was not particularly deep and may be another area where there could be learning from the extensive work done on stigma in the field of HIV/AIDS. There was no literature available on possible responses to NTD related stigma and discrimination – neither on trainings for health care providers, social and behavior change communication (SBCC) to change community attitudes, nor on empowerment programs or support groups for those affected.

Analysis of the available sex disaggregated data in relation to MDA coverage is not particularly conclusive, with general patterns of equity in coverage at the national level<sup>23</sup> but with very little sub-national data available to parse out how this varies between districts and or regions.

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<sup>23</sup> In fact, for 16 countries considered by the Cohn et al. study, coverage was found to be slightly higher for women than for men.

Across the program countries, with the exception of Ghana, the CDD roles and paid MDA-related staff were disproportionately held by men. There were several explanations put forth for this, from bias in the selection process to gender norms making it challenging for women to safely take on these roles, particularly the CDD role. However, there is also evidence that women are often more effective as CDDs when compared to men.

For the most part, the literature did not examine the role that power plays in impacting women's vulnerability to NTDs, including participation in MDAs. How do power dynamics in the home affect whether women access treatment? Who decides whether a pregnant woman will accept treatment? How does power affect whether women serve as CDDs? There was a brief mention of husbands being angry at female CDDs for their work taking them away from household duties. The data cited earlier from Senegal, Niger, Burkina Faso, Côte d'Ivoire and Cameroon showed that 80% of married women aged 15 to 19 years old do not have the final say on their own healthcare. This suggests that household power dynamics may be the single most important factor in women's participation in treatment programs, particularly for married and pregnant women.

The ultimate abuse of power is GBV, which is most often experienced by women, and used to enforce norms for femininity. There is a significant overlap between GBV and HIV leading directly to women's infection but also affecting their ability obtain testing for HIV and adhere to treatment. It may be possible to draw from the experience and best practices in the field of HIV and GBV to identify and address how power dynamics play out at the family and community levels in relation to NTDs, including potential escalation to GBV to enforce gender norms.

Lastly, we examined ways that the NTD program could be used to promote gender equality. Some literature suggests that de-worming programs in schools contribute to gender equality by increasing education, economic opportunities and empowerment of girls. Another potential area where programs could contribute would be through changing harmful gender norms via targeted SBCC strategies – for example, changing norms around stigma, discrimination, as well as expectations around gender roles or perceptions of women's suitability to serve as CDDs. But there was no literature or program reports on this topic area. And a final opportunity for programs to promote gender equity would be through increasing women's participation in human resources for the program whether as CDDs or in leadership positions. Women's participation as CDDs is important since it may affect the proportion of females reached as well as improve MDA outcomes in general. But it is important to keep in mind that it is not necessarily empowering, particularly if it leads to an increase in women's unpaid labor and yields no other non-monetary benefits. In fact, current gender analysis guidance specifically calls for the analysis of the gender inequities in paid, unpaid and community labor, and monitoring for differential impacts and unintended consequences of development programs (USAID, 2013). This is particularly important given that health programs increasingly rely on women's unpaid labor – whether as family planning volunteers, HIV outreach workers, TB workers, or NTD workers. Concern is also raised when paid positions are disproportionately male and there is no pathway for unpaid female workers to move to paid positions. In summary, depending on the context, serving as a CDD could be seen as an empowering experience or an exploitative one for women.

The chief opportunity for the Act to End NTDs | West program is to use this gender analysis (and ensuing strategy, once available) to integrate gender considerations into programming as soon as possible, to encourage countries to gather appropriate data to inform gender issues, and to make those data better understood and used for decision-making at the national and sub-national levels.

## Conclusion and recommendations for further study

While most targeted NTDs, aside from trachoma, appear to infect males and females at similar rates, the impacts of living with NTD infections often leads to much more severe health and social impacts for women and girls.

Through the next phase of this gender analysis, it will be essential to investigate how men and women, boys and girls, including those with disabilities, are targeted and reached by social and behavior change communication (SBCC) messaging around prevention and participation in MDA, as there was no information on this found in the literature review.

The literature review presented various ways that females, males, persons with disabilities, or other marginalized individuals might be disproportionately missed through MDAs, but the available quantitative data did not provide a clear picture as to what degree this was happening across program implementation sites. For the next phase of this gender analysis (Phase II), Act to End NTDs | West will complete a quantitative study, currently underway, that analyzes available coverage and prevalence data for the 11 countries supported by the program. Phase II of the study will also use qualitative findings to understand the reasons behind any disparities in MDA coverage, as well as ways to engage women and other disadvantaged subpopulations in decision-making, program implementation, and problem solving. This will ensure the Act to End NTDs | West program is able to meet its objectives in an equitable and gender sensitive way that improves the lives and health of communities across 11 countries in West Africa.

As we move into Phase II of this gender analysis study, we will finalize our selection of countries for in-country qualitative data collection, with the assistance of country program staff. We recommend that selected countries be as representative as possible, and therefore include countries with both majority Muslim and majority Christian populations as a point of comparison; countries that pay CDDs as well as those that don't; countries with high rates of female CDDs as well as those with lower rates; and at least one country with a generalized HIV epidemic to look into HIV and schistosomiasis coinfection. Due to security considerations, we will not conduct qualitative data collection in program countries with high levels of political instability.<sup>24</sup>

As a result, we propose to conduct in-country data collection in Sierra Leone (majority Muslim and one of the only country that pays its CDDs); Cote d'Ivoire (has a majority Muslim population in the north, and majority Christian in the south, generally and has a generalized HIV epidemic); and Ghana (has on average more female than male CDDs; and is majority Christian). In the case of unforeseen delays in local IRB processes, we could also consider replacing one of these countries.

Prior to the fieldwork, we will review our findings from this first phase with key technical and programmatic Act to End NTDs| West staff to gain a deeper understanding of some of the findings. We will further investigate some of the more interesting findings from the quantitative analysis during fieldwork. For instance, the reasons for the high percentage of female CDDs in Ghana warrants further

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<sup>24</sup> Unfortunately, these cover the Sahel countries of Mali, Niger and Burkina Faso, where the unique traits of this set of countries would have been of interest to explore, had security not be a concern.



exploration during the qualitative data collection – to see why, unlike other countries, there were no barriers to hiring female CDDs in this country. As a second example, in Sierra Leone, for other MDA staff, including M&E staff, females were trained at a dramatically higher rate than men. Again, the positive results in Sierra Leone warrant further investigation during the qualitative field work

Within these more in-depth country studies, we will focus on additional information from national and subnational gender and empowerment indicators (if they exist) and study how they relate to NTD elimination and control efforts; how NTDs are, or could be, integrated into other health interventions that target diseases such as AIDS, cervical cancer and other STIs with the goal of addressing gender disparities; identify any existing district level data to identify gaps in coverage or outcomes and potential gender related considerations; how SBCC programming is targeting and reaching vulnerable populations; the impact of disability on NTD treatment; the differential access to MDA through school or community based campaigns; and how the program can improve outcomes through additional focus on gender and social inclusion as well as how the program itself can increase equity and empowerment of women and girls and other vulnerable populations.

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