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# USAID's Act to End Neglected Tropical Diseases | West Gender Analysis: Phase 1 Desk Review March 2019



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## List of Acronyms

ADS – Automated Directives System

CDD – Community Drug Distributor

DALY – Disability-Adjusted Life Year

FGS – Female genital schistosomiasis

GBV- Gender-based Violence

LF – Lymphatic Filariasis

MDA – Mass drug administration

MEL – Monitoring, evaluation, and learning

NTD – Neglected tropical disease

PC – Preventative chemotherapy

SBCC – Social and behavior change communication

SCH - Schistosomiasis

STH – Soil-transmitted helminths

STI – Sexually transmitted infection

TT - Trachomatous trichiasis

UNAIDS - The Joint United Nations Programme on HIV/AIDS

USAID – The United States Agency for International Development

WHO – World Health Organization

## 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>1</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>2</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. While sex-disaggregated MDA program coverage data is aggregated at the national level, the sex-

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<sup>1</sup> The NTDs covered by the program include: trachoma, lymphatic filariasis, onchocerciasis, schistosomiasis, and three soil transmitted helminths (hookworm, roundworm and whipworm).

<sup>2</sup> The countries are: Benin, Burkina Faso, Cameroon, Cote D'Ivoire, Ghana, Guinea, Mali, Niger, Senegal, Sierra Leone, and Togo.

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>3</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 (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

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<sup>3</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)

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.

### 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

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 (Hofstraat 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 (Hofstraat et al., 2016). The same systematic review on NTDs and social stigma (Hofstraat 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. Hofstraat 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 (Hofstraat 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 (Katarwa, 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>4</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>5</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%).

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<sup>4</sup> Ghana is likely to be one of the countries visited during the qualitative field work.

<sup>5</sup> Sierra Leone is also likely to be one of the countries visited during the qualitative field work.

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 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; Katarbarwa 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; Katarbarwa 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 (Katarbarwa 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 (Katarbarwa 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>6</sup> but with very little sub-national data available to parse out how this varies between districts and or regions.

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

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<sup>6</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.

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>7</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

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<sup>7</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.

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 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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