Ghana Disability Data Disaggregation Pilot Project: Results of Integrating Disability into Routine Data Collection Systems

2016 - 2018

Sightsavers

Contents

List of acronyms and abbreviations

ANC	Antenatal care
CDD	Community drug distributor
CBS	Community based surveillance
CHN	Community health nurse
CWC	Child welfare clinics
DDD	Disability data disaggregation
FGD	Focus group discussion
FP	Family planning
IDI	In-depth interviews
ITN	Insecticide treated nets
LEAP	Livelihood Empowerment Against Poverty
LF	Lymphatic Filariasis
MDA	Mass drug administration
NID	National immunisation days
NGO	Non-governmental organisation
NTD	Neglected Tropical Diseases
PWD	Person with a disability
SDGs	Sustainable Development Goals
WGSS	Washington Group Short Set

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Acknowledgements

We would like to thank all people who provided support and guidance to this pilot, including the Ghana Ministry of Health, Ghana National Health Service, Ghana Neglected Tropical Disease (NTD) Programme, Sightsavers global Research team, Sightsavers NTD team, Sightsavers Country Office in Ghana as well as health workers, programme managers and Community Drug Distributors. Many thanks to Irish Aid for financial contributions to this project.

Executive Summary

There are an estimated one billion people with disabilities across the world[i], yet there remains a lack of accurate and comparable data on disability globally. This lack of data often means that decisions made by governments and other stakeholders allocate resources in a way that excludes people with disabilities, which reinforces existing inequalities. This is further compounded within international development programmes, as many development organisations do not collect data to measure the inclusion of people with disabilities in programmes at national and sub-regional levels (2).

In recent years, Sightsavers has been looking at the intersection between its two main streams of work: health and disability inclusion. One of the areas of focus has been to understand how people with disabilities are included within health projects in Africa and Asia. In 2014, Sightsavers launched two pilots where we tested how to collect data on clients' disability status in urban India and in rural Tanzania, using the Washington Group Short Set of Questions (WGSS)

Following reflection and discussion, it was decided that a third pilot would be established to understand how data may be collected in a system where community members were responsible for delivering interventions and collecting data on intervention uptake. It was anticipated that the pilot will help to refine the analysis of data, strengthen local Health Information Management Systems (HMIS) and improve programme quality not only in Ghana but in the West Africa region and beyond. Discussions with colleagues in the Ghanaian country office highlighted an interest to test collecting disability data within the Neglected Tropical Disease (NTD) programme that they conduct in partnership with the Ghana National Health Service.

The overall aim of the pilot was to develop and test a way to capture data on disability within the onchocerciasis and lymphatic filariasis Mass Drug Administration (MDA) data system. Within the project, specific objectives that were identified by the country team were:

- To train NTD officers to collect and analyse data on disability
- To identify the proportion of MDA beneficiaries who have disabilities
- To identify the proportion of registered PWDs benefitting from MDA each year
- To identify the types of disabilities affecting person who access MDAs
- To advocate for more accessibility for people with disabilities in the NTD programme and other related programmes based on data collected under this project
- To advocate for more disaggregation of data in the NTDs programme

The pilot phase of the Ghana disability data disaggregation (DDD) project was carried out in two districts of the Brong Ahafo region: Kintampo North District and Tano South District. The target population of this project comprised the MDA project implementers from national, regional, district and community level (health workers, disease control officers at district levels, and Communities Drug Distributors (CDD)) and household members of these communities.

Methods

A mixed design combining qualitative and quantitative methods was used to explore the different experiences of project implementation at various stages from national, regional, district and community level.

The project was designed to be embedded within the MDA programme with the aim of ensuring efficiency and sustainability. A qualitative approach including both in-depth interviews (IDIs) and focus group discussions (FGDs) was used to document stakeholders' views at all levels concerning the implementation process.

A quality audit process using a quantitative approach was also carried out in six communities of the two project districts.

Existing data collection tools were adapted to include space for disability data; these were the community registers used by CDDs and forms used at sub-district and district levels. At the level of the MDA project implementer, data was collected using various qualitative data collection approaches including in-depth interviews, focus group discussions and workshop discussions. A short questionnaire was developed in order to collect data during the audit process.

Results

In Tano South, data was collected from 22,572 people in 39 communities in the first round of data collection (Round 1) and from 21,982 people in 37 communities in the second round of data collection (Round 2). In Kintampo North, data was collected from 61,774 people in 73 communities in Round 1 and from 63,762 people in 76 communities in Round 2. Overall treatment coverage rates in Tano South were 83.8% in Round 1 and 80.7% in Round 2. In Kintampo North they were 81.4% in Round 1 and 82.5% in Round 2.

The prevalence of disability (using the WGSS – 'a lot of difficulty' or 'cannot do at all') varied considerably between villages as well as between rounds. In Tano South, 0.8% of those registered reported having a disability in Round 1, raising to 3.2% in Round 2. The range between the villages remained similar, from a minimum of 0% in both rounds, to a maximum of 16.5% in Round 1 and 15.1% in Round 2. In Kintampo North, there was a similar increase between Rounds 1 and 2: the prevalence in Round 1 was 1.7% and in Round 2 was 3.4%. The range between the villages decreased significantly in Round 2. The minimum prevalence among the villages was 0% in both rounds; however, the maximum in Round 1 was 63.4% and in Round 2 was 31.4%.

Among those people identified as having a disability in Tano South in Round 1, 100% received MDA treatment compared to 83.8% overall. In Round 2, the proportion of people with disabilities taking the treatment in this district was slightly lower (91.5%) and so was among the total population (80.7%). In Kintampo North in Round 1, 91.3% of those identified as having a disability received treatment compared to 81.4% overall. In Round 2, the proportion of those taking drugs among people with disabilities was higher (99.8%); the proportion in the total population increased slightly to 82.5%. We found that people with disabilities had nearly seven times greater odds of receiving treatment than people without disabilities, even following adjustment for factors such age and sex.

From the audit data, the results show that during Round 2, 3.7% of community members enumerated reported disability ('a lot of difficulty' or 'cannot do at all') in seeing, 1.7% in hearing, 4.0% in walking or climbing and 2.3% in remembering or concentrating. The proportion was similar in both rounds.

Conclusion

The pilot showed that collecting data on disability through MDA programmes is feasible and has a number of programmatic benefits. The main positive outcome was the change in health provider attitudes and perceptions towards disability. Following receiving the training in the WGSS, health providers and CDDs were better able to understand the needs of people with disabilities and the importance of equitable access to health services. The project also improved communication between health workers, CDDs and people with disabilities. This pilot showed that planning and monitoring are a critical element to put in place in order to collect quality data on disability, and time should be allocated to training and sensitisation.

1. Background

Sightsavers is an international non-governmental organisation (NGO) working to eliminate avoidable visual impairment and improve equality of opportunities for people with disabilities. In recent years, Sightsavers has been looking at the intersection between its two main streams of work: health and disability inclusion. One of the areas of focus has been to understand how people with disabilities are included within the Sightsavers-supported health projects delivered in partnership with local Ministries of Health and other health providers in Africa and Asia. This area of work has also provided a useful platform for engaging with global discussions on the Sustainable Development Goals (SDGs), 'leave no one behind' pledge and opportunities for measuring inclusion.

In 2014, Sightsavers launched two pilots where we tested how to collect data on clients' disability status within routine Health Information Management Systems (HMIS). One was an urban eye health project conducted with a private hospital and a community-based partner in urban India, and the other was a trachoma surgical camp project conducted with the Ministry of Health in rural Tanzania. Both projects were completed successfully, and the results and conclusions can be found in the corresponding reports[ii]. Key lessons of the initial two pilots showed that:

- Planning and monitoring are key to collecting quality data, and time should be spent on adapting the data collection processes and tools, translating the questions and training/ sensitising stakeholders and data collectors.
- Data collection systems can be resistant to change, and an iterative process may be required to refine processes and tools.
- Analysis, and therefore use of the data, was a weak part of the system which needed reconsidering and refining.

It was a feature of both the India and Tanzania pilots that paid staff – either administrators or health providers themselves – collected disability data. However, in many Sightsavers projects, data is collected by community volunteers who may have less education and less motivation to perform 'extra' tasks (as collecting data on disability may be perceived) and so questions remained about how data could be collected in those projects, notably MDA/NTD projects.

Following reflection and discussion, it was decided that a third pilot would be established to understand how data may be collected in a system where community members were responsible for collecting data, and how to improve and refine the analysis component of the data system. Discussion with colleagues in the Ghana Country Office highlighted an interest to test collecting disability data within the NTD programme that they conduct in partnership with the Ghana National Health Service.

This report describes how the pilot in Ghana was conceptualised and carried out (Methods), reports the data captured and the process of conducting the pilot (Results), and discusses the implications of the project for future work in Ghana and similar contexts in West Africa and beyond (Discussion). Conclusions summarise the project outcomes and suggest areas for future work based on the evidence presented here. The project proposal, schedule and budget are shown in Appendices 1-3.

2. Aims and objectives of the pilot

The overall aim of the pilot was to develop and test a way to capture data on disability within the MDA data system. Based on recommendations from the previous two pilots, there was a particular emphasis on developing and testing a way for the data to be consolidated and analysed locally.

Within the project, specific objectives that were identified by the country team were:

- To train NTD officers to collect and analyse data on disability
- To identify the proportion of MDA beneficiaries who have disabilities
- To identify the proportion of registered people with disabilities benefitting from MDA each year
- To identify the types of disabilities affecting person who access MDAs
- To advocate for more accessibility for people with disabilities in the NTD programme and other related programmes based on data collected under this project
- To advocate for more disaggregation of data in the NTDs programme

Additionally, an evaluation framework based on the previous DDD pilots was developed that outlined learning questions for the project to answer (Appendix 4).

3. Methods

3.1. Project background

The Onchocerciasis and Lymphatic Filariasis (LF) Elimination programme in Ghana is a nationwide MDA programme (Box 1).

Box 1: Mass Drug Administration (MDA)

MDA is a process where prophylaxis drugs, or preventative chemotherapy, are administered to entire communities regardless of disease status. In areas where certain infectious diseases are endemic, everyone may be considered ‘at risk’ and so routine, campaign-style programmes target all eligible community members with low-dose drugs proven to prevent asymptomatic infections and prevent reinfection with the eventual aim of eradicating the disease from the community entirely.[iii]

MDA is a key intervention in eradicating many of the world’s neglected tropical diseases, including onchocerciasis and LF. Ivermectin and Alebendazole are the drugs given at regular intervals to eligible members of communities where onchocerciasis and LF are endemic to reduce the disease burden with a view to eventually eliminating them.

In most countries, MDA is delivered in partnership between the government and the affected communities. Representatives nominated from within their communities are identified to work with local health workers to deliver and monitor the MDA programmes. These individuals are often called community drug distributors (CDDs) and they are often chosen by their communities for their literacy and trustworthiness. The CDDs are trained by health workers to first conduct a census within their communities to understand who lives there and who is eligible to participate in the MDA programmes; secondly, to distribute the drugs to the community members; and finally, to act as a first point of call in case of any side effects or need to refer to medical facilities.

In Ghana, MDA activities commence with cascading training sessions, which begin at the national level. Participants of the national level training are regional supervisors who in turn go and train district supervisors at the regional level. The district supervisors then move to the district level to train sub-district supervisors. Finally, the sub-district supervisors invite all the CDDs to the sub-district level and train them. Following the training, the CDDs commence sensitisation and registration in their communities. The CDDs move from house to house to register all new entrants, including babies that have been born, and to remove the names of individuals who have left the community permanently or are deceased. This process ensures that community registers are up to date to enable all eligible members in the community to participate in the MDAs, although in reality shortages of resources have meant the enumeration has not always happened.

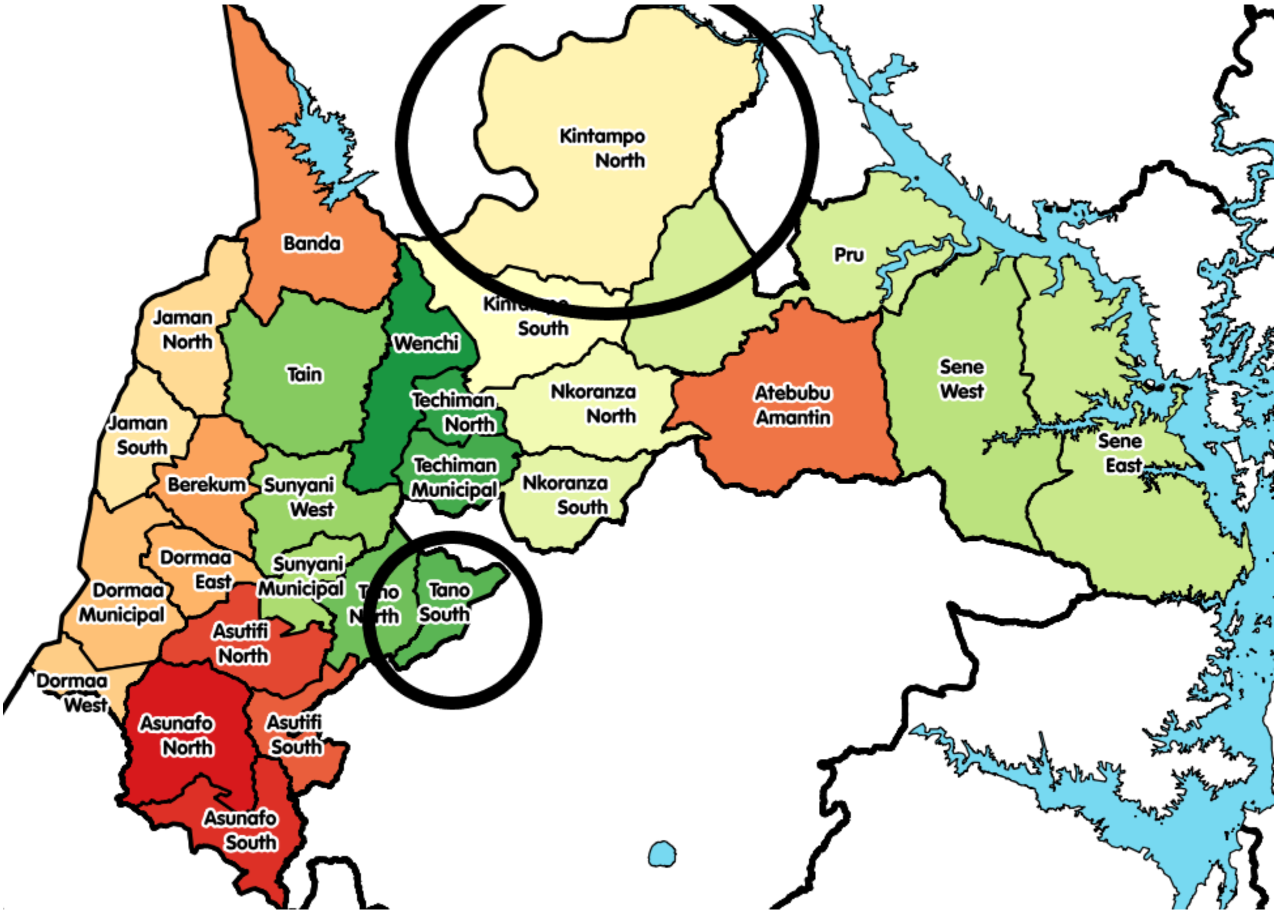
Drug distribution commences after the community registrations are completed and continue for two to three weeks. This is also carried out by the CDDs who move from house to house using the community registers they had just updated. A cascading supervisory system is used to ensure that each level of the MDA implementation is supervised by the next higher level, using a monitoring and supervision checklist. Thus, the national level supervisors supervise regional level supervisors who also supervise district level supervisors. District level supervisors supervise sub-district staff who supervise the CDDs.

The MDA programme in Ghana has had a number of challenges including inappropriate CDDs in some communities, poor data quality and inadequate supervision. Limited resources meant that fewer CDDs and supervisors could be trained to support the MDAs. Thus, in some of the communities, the CDDs have more people than they can effectively register and administer the drugs to. Monitoring activities over the years has revealed that many people in the communities had not registered and were therefore not participating in the MDAs. The factors responsible for this included refusal of the community members to register because they did not want to take the drug and the inability of the CDDs to update their registers regularly.

3.2 Project setting

The pilot phase of the disability data disaggregation project was carried out in two districts of the Brong Ahafo Region: Kintampo North and Tano South (Figure 1)

Figure 1: Figure 1: Ghana - pilot project location



3.3. Overview of project design

Following informal discussions between the Sightsavers DDD pilot team and the Ghana Country office where it was agreed to plan a pilot to test DDD in the MDA process, a project proposal was developed to flesh out the concept (Appendix 1) in April and May 2015.

The project was designed around two guiding principles: integration and relevance. Firstly, the DDD pilot project was to be integrated within the existing MDA processes to ensure efficiency and sustainability. Thus, the same tools, people and processes for implementing and monitoring the MDAs were to be adapted and used for the pilot project. The second principle is that the pilot project, apart from collecting data on persons with disabilities, must contribute to the success of the MDA in order to make it more relevant. This was achieved by identifying gaps in the existing MDA implementation and using the DDD pilot project as an opportunity to address them.

The pilot project therefore adapted two key activities that were meant to improve the MDAs implementation. The first is the registration process, which enabled the districts to have accurate population data of people in the endemic communities and post MDAs review, which helped the districts to review their performance during the MDAs and take the required actions for improvement. The post MDA review also provided an opportunity for the MDA data to be validated. Both processes, though important for the MDAs, were not being carried out optimally due to the limited numbers of community volunteers and supervisors assigned in various communities to meet the population and, more particularly, due to the lack of funding. Also, there was lack of precision on the type of data to be collected, which is evidenced by the different types of variables reported in both round 1 and round 2 of data collection. In fact, post MDAs review at the district levels had completely stopped prior to the DDD pilot.

Therefore, the activities of the pilot project included:

Pre-data collection

- Sensitising project managers at Ghana Health Service on disability and collecting the data
- Sensitising and training health workers at district, sub-district and local levels on disability and collecting and analysing disability data
- Sensitisation and training CDDs on disability and collecting disability data
- Sensitising community leaders on the additional data that will be collected
- Adapting community registers used by CDDs to include space for disability data
- Developing forms for data aggregation, based on the forms used at sub-district and district levels (Appendix 5).

Post-data collection

- Conducting qualitative data collection activities with project stakeholders to answer evaluation questions
- Discussing experiences in post-MDA debrief

Sensitisations and training of project managers, health workers, CDDs and communities

For this project, all stakeholders were mapped (Appendix 6) and the level and type of knowledge they needed to have about the pilot was discussed. Certain stakeholders, for example project managers and community leaders, were thought to need to know about the project, its aims and how it would affect them and the people they represent. Sensitisation meetings were held where they would have the opportunity to find out about the project and ask questions.

Other stakeholders, generally those more closely involved in data collection and management, were considered to need extra information and were provided with a more comprehensive training package. MDA training generally is delivered through a cascade system where national level staff deliver training to district health staff, and thus down the administrative levels to CDDs themselves. The disability data training was designed in the same way so that an initial training was delivered at the district level in the two pilot areas, and then those staff themselves delivered the training to the CDDs in the project areas.

One additional day was added to the number of days used for training at the district and sub-district levels during the MDA. Training materials were developed including a number of PowerPoint presentations and an infographic hand-out to remind CDDs about asking the questions and capturing the data. The four training modules covered the following areas:

1. Introduction to the pilot project
2. Sensitisation on disability
3. Introduction to the Washington Group questions
4. Analysis of data (for district and sub-district staff only)

The training included time for participants to practise asking the questions in different simulated scenarios to understand where difficulties may lie, and to smooth out any issues.

Community registration and drug distribution

This activity was adapted and strengthened as part of the DDD project to improve accessibility, register people with disabilities and ensure accurate population data for the MDAs.

During registration, the CDDs moved from house to house to register everyone in the community and ask the Washington Group Short Set of Questions (WGSS), which had been translated into local languages, to identify people with disabilities (Box 2). People who were identified as having disabilities had ‘WD’ - which represented ‘with disabilities’ - written in front of their names.

Post MDA Review

This meeting was organised to receive feedback from the project implementers regarding their experiences during the implementation, as well as the success and the challenges they identified. The outcome of this meeting would inform the next MDAs. This is another activity introduced by this project to improve both the MDAs and the disability data collection process.

Box 2: Measuring disability in the community

Disability as a concept is understood in many ways. Similarly, approaches to assessing whether an individual is disabled or not vary greatly between and within countries. Recently, there have been international movements to agree a global measurement that would allow for clear cross-country comparisons of disability data and this has been led by a United Nation's Statistical Division City Group, the Washington Group on Disability Statistics.

The Washington Group was formed by the United Nations Statistical Commission in order to facilitate the collection of comparable national-level disability data. A series of question sets have been designed to operationalise the WHO's International Classification of Functioning, Disability and Health (ICF) into national surveys and censuses. The Washington Group Short Set of Questions (WGSS) operationalise disability as a measure of how an individual may be excluded from participation in everyday activities because of difficulties they face in functional domains due to a health problem.

The WGSS has been endorsed by the United Nations. It is a standardised set of questions that can be used in different contexts and settings to inform policies, systems and services. With appropriate training and sensitisation, the WGSS allows more accurate data collection and international comparisons on disability data that are operational/feasible.

The WGSS

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM:

1) Do you have difficulty seeing, even if wearing glasses?
2) Do you have difficulty hearing, even if using a hearing aid?
3) Do you have difficulty walking or climbing steps?
4) Do you have difficulty remembering or concentrating?
5) Do you have difficulty (with self-care such as) washing all over or dressing?
6) Using your usual (customary) language, do you have difficulty communicating (for example understanding or being understood by others)?"

Response categories:

a) No, no difficulty
b) Yes, some difficulty
c) Yes, a lot of difficulty
d) Cannot do it at all

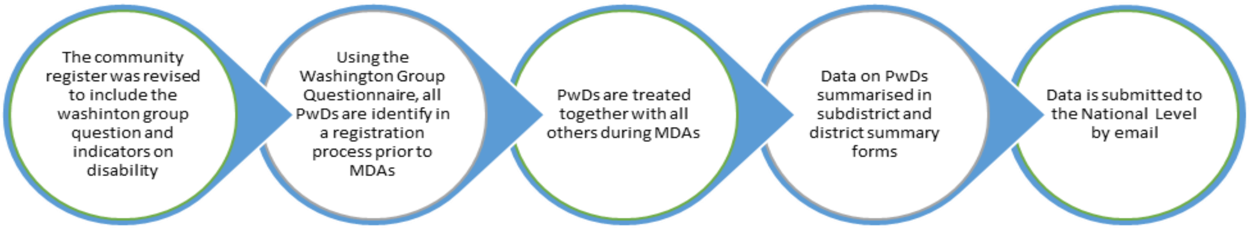
The responses that may constitute disability can be altered depending on what the data collector wishes to understand. However, in most cases, we consider people to be disabled if they have a lot of difficulty or cannot do at all in any one of the six domains.

3.4. Data collection

Data collected in this pilot project was not only the disability data, but also data required to answer the evaluation questions specified in the evaluation framework (Appendix 4). Both quantitative and qualitative data were collected.

The existing MDA data collection system was mapped, and the documents and processes that required adaptation were identified and reviewed. Figure 2 shows how DDD data flows from the community level to the national level

Figure 2: DDD Data Flow Chart



In this pilot, CDDs were trained on basic concepts around disability as well as the WGSS. They were inducted on the amended forms and taught to determine whether someone was disabled or not according to their responses to the WGSS. CDDs recorded each answer to the six questions and also summarised whether an individual was disabled or not according to the responses. It is this summary status of disability that was transferred into sub-district and district aggregated records.

Quantitative data was extracted from the community registers maintained by CDDs and included age, sex, disability status and treatment status of individuals. Forms were designed for collating data from the community register at the sub-district and the district levels.

Additionally, three communities in each of the two pilot districts were chosen to have their data audited to measure how accurately data was being transferred from the CDD registers through the aggregation process at district and sub-district levels. Auditors were sent to local health centres where the community registers of the CDDs in the six communities were stored, and copied the data exactly into Excel sheets including the individual answers to each of the six WGSS questions.

A quality audit of the data collection was carried out in six communities of the two districts in Round 1 and Round 2:

- Round 1: Kintampo North (Benkrom, Adomano, Kaakra Akura) and Tano South (Ankaase Unit 1, Nkwakyire Unit 2 and Tougyankrom Unit 1).
- Round 2: Kintampo North (Benkrom, Adomano, Kaakra Akura) and Tano South (Nsuta, Adaa Unit 2 and Derma Unit 1A).

Qualitative research approaches were used to capture data on perceptions and experiences: in-depth interviews (IDI) were conducted with key health workers and focus group discussions (FGD) were conducted among CDDs. Topic guides were developed in advance, drawing on the evaluation framework (Appendix 4).

3.5. Data management and analysis

Audio recordings of FGDs and IDIs were transcribed verbatim and supplemented by hand notes. Codification was done on Nvivo informed by a framework analysis plan developed a priori and based on the evaluation plan.

Quantitative data from the district and sub-district summaries were reviewed and basic summary statistics were calculated. The in-depth analysis was limited to the audit data. Once all audit data was captured, a complete dataset was established and cleaned, and data was analysed using the statistical software, Stata. Simple statistics (total counts, proportions, averages and ranges) were used to analyse this data and represent in the form of frequency tables. Chi-squared tests and logistic regression were used to calculate odds ratios to measure the uni and multi-variate relationships between explanatory variables and the outcome of interest (having received treatment or not) during Round 2 enumeration. These analyses were not performed on the Round 1 enumeration because of the absence of the interest variable (having receiving treatment). Confidence intervals and p-values are shown that describe the likelihood of the relationships observed being true or statistical anomalies. Small p-values (generally less than 0.05) are accepted as an indicator that the measure observed is true and not an anomaly.

3.6 Chronogram

Appendix 2 shows the planned versus real timeline of the project.

3.7 Budget

The final budget for the activities is shown in Appendix 3.

4. Results

4.1. Reported numbers of people with disabilities

The data below describes the results of the MDA data collection aggregated from community registers through sub-district and district summaries from two rounds of MDA: Round 1 in 2016, and Round 2 in 2017, for both Tano South and Kintampo North. Both districts reported on four indicators:

1) Number of persons registered
2) Number of persons with disabilities
3) Number of persons with disabilities treated
4) Number of persons with disabilities refusing treatment

The number of villages varied in both districts between both rounds. In Tano South, data was collected from 22,572 people in 39 communities in Round 1 and from 21,982 people in 37 communities in Round 2 (Table 1). In Kintampo North, data was collected from 61,774 people in 73 communities in Round 1 and from 63,762 people in 76 communities in Round 2.

The prevalence of disability varied considerably between villages as well as between rounds, but generally was comparable to data collected during the national census (see section 4.4 below). In Round 1 in Tano South, 0.8% of those registered reported having a disability (a lot of difficulty or cannot do at all). In Kintampo North, it was 1.7%. In Round 2, the prevalence of disability was higher in both districts (3.2% in Tano South and 3.5% in Kintampo North). The range between the villages remained similar in Tano South, from a minimum of 0% in both rounds to a maximum of 16.5% in Round 1 and 15.1% in Round 2. In Kintampo North, the range between the villages decreased significantly in the second round. The minimum prevalence among the villages in this district was 0% in both rounds; however, the maximum in Round 1 was 63.4% and in Round 2 was 31.4%.

Table 1: Total number of people registered and prevalence of disability in districts, by MDA Round.

		Number of communities	Number of people registered	Number of people identified as having a disability	Prevalence of disability (range in villages)
Tano South	Round 1	39	22,572	180	0.8% (0-16.5%)
	Round 2	37	21,982	707	3.2% (0-15.1%)
Kintampo North	Round 1	73	61,774	1,081	1.7% (0-63.4%)
	Round 2	76	63,762	2,244	3.51% (0-31.4%)

4.2 Treatment uptake by disability status

Among those people identified as having a disability in Tano South in Round 1, 100% received treatment compared to 83.8% overall (Table 2). In Round 2, the proportion of people with disabilities taking the treatment was lower (91.5%) and it also decreased among the total population to 80.7%. In Kintampo North in Round 1, 91.3% of those identified as having a disability received treatment compared to 81.4% overall. In Round 2, the proportion of treatment among people with disabilities increased to 99.8%; it also marginally increased among the total population to 82.5%. Although the samples were relatively small, the findings indicate good uptake of treatment among people identified as having a disability compared to their non-disabled counterparts.

Table 2: Total people treated and number of refusals, and people with disabilities treated and refusals

		All people registered	All people treated n (%)	People with disabilities n	People with disabilities treated n (%)
Tano South	Round 1	61,774	51,767 (83.8)	180	180 (100)
	Round 2	63,762	51,430 (80.7)	707	647 (91.5)
Kintampo North	Round 1	22,572	18,379 (81.4)	1,081	987 (91.3)
	Round 2	21,982	18,135 (82.5)	2,244	2,240 (99.8)

4.3 Audited data: Round 1 and Round 2

Round 1 audit data

Immediately after the first implementation of the Ghana DDD, data was collected from six communities in Kintampo North and Tano South by independent data collectors. This data was analysed and compared to data provided from the MDA. Table 3 below summarises the missing data identified during Round 1 audit data.

Table 3: Summary of missing data from audit records Round 1

	Number of missing data for key variables							
Community	**Age**	**Sex**	**Q1**	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**
Kimtampo								
Benkrom (n=1,055)	0	3	0	0	0	0	0	0
Adomano (n=422)	0	3	0	0	0	0	0	0
Kaakra Akura (n=124)	0	0	0	0	0	0	0	0
Tano South								
Ankaase Unit 1 (n=738)	0	0	0	0	0	0	0	0
Nkwakyire Unit 2 (n=108)	0	0	0	0	0	0	0	0
Tougyankrom Unit 1 (n=352)	0	0	0	0	0	0	0	0

It was found that there were no significant issues with the data collected from the two districts during the Round 1 audit process.

Round 2 audit data

The data collected from the six audit communities in the two study districts in Round 2 was also analysed and compared to the data provided through the MDA system. In this round, the audited data had been transcribed by independent data collectors from the original CDD registers into an Excel sheet for separate analysis. Table 4 summaries missing data in the CDD registers according to the audited records in this round.

Table 4: Summary of missing data from audit records Round 2

	Number of missing data for key variables							
Community	**Age**	**Sex**	**Q1**	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**
Kimtampo								
Benkrom (n=1,445)	0	3	3	5	4	4	7	13
Adomano (n=490)	0	3	1	0	1	1	1	1
Kaakra Akura (n=170)	0	0	0	0	0	0	0	0
Tano South								
Nsuta (306)	0	0	0	0	0	0	0	0
Adaa Unit 2 (179)	0	0	0	0	0	0	0	0
Derma Unit 1A (673)	0	0	0	0	0	0	0	0

The audited data itself shows a few issues which we should understand in order to interpret the results correctly. Data from Kaakra Akura in Kintampo North look complete; however, there were seven data points collected for each person for only six questions calling into question the accuracy of either the original CDD data collection or the transcription of the data for the audit. The other two communities show a few missing data points in other categories, although relatively small in number.

We also tried to collect similar data from Tano South, however there were significant issues with the data collected. For example, instead of listing all the responses to each of the six questions, one column was completed indicating a code signifying a level of difficulty (and in some cases more than one). A second column was completed indicating which functional area the level of difficulty was experienced. In this column, it was impossible to reconcile the two columns if difficulties were experienced in more than one domain. 592 entries were transcribed as part of the audit and every single individual had at least some difficulties in at least one domain, which seems unfeasible and indicates poor understanding of implementation of the WGSS in that district.

4.3.1 Detail analysis of the audited data of Round 1 and Round 2

Descriptive analysis

The data audit in the six communities recorded data from 2,802 community members who had been recorded in the registers during Round 1 and from 2983 community members who had been recorded in the register during Round 2. The average age was 26 years in both rounds. Females were slightly more represented during this enumeration: 50.6% in Round 1 and 51.5% in Round 2. In total, 78.9% of the people enumerated received treatment during Round 2. Unfortunately, this variable was not collected in the entire locality during Round 1 audit data. (Table 5)

Table 5: Description of variables Round 1 and Round 2

Round 1				**Round 2**			
	Category	**Frequency (n=2,802)**	**Percentage**		**Category**	**Frequency(N=2,983)**	**Percentage**
District	Kintampo North	1,602	57.2	**District**	Kintampo North	1,824	61.2
	Tano South	1,200	42.8		Tano South	1,159	38.9
Locality* **(n=2,800)**	Ankaase unit 1	738	26.4	**Locality**	Adaa Unit 2	177	5.9
	Adomano	423	15.1		Adomano	423	14.2
	Benkrom	1,055	37.7		Benkrom	1,259	42.2
	Kaakra Akura	124	4.4		Derma Unit 1A	678	22.7
	Nkwakyire Unit2	108	3.9		Naaba Kura	142	4.8
	Tougyankrom Unit 1	352	12.6		Nsuta	304	10.2
Treated**				**Treated**	No	629	21.1
					Yes	2,354	78.9
Sex* (n=2,794)	Female	1,381	49.4	**Sex**	Female	1,535	51.5
	Male	1,413	50.6		Male	1,448	48.5
Age categorical* **(n=2,799)**	≤15	1,115	39.8	**Age**	≤15	1,080	36.2
	16-39	1,071	38.5		16-39	1,236	41.4
	40-49	258	9.2		40-49	282	9.5
	50-59	178	6.5		50-59	168	5.6
	60+	177	6.3		60+	217	7.3

*presence of missing data

**variable not collected during this round

Description of disability data

Overall, it was found 214 (7.6%) of people had a functional disability during Round 1 and 269 (9.0%) in Round 2 (Table 6). Respectively, 52 people (1.8%) and 75 people (2.8%) reported difficulties in two or more domains during Round 1 and Round 2 (Table 6).

Table 6: Description of the disability status

	Round 1				**Round 2**	
Variable	**Category**	**Frequency (n=2,802)**	**Percentage**		**Frequency (n=2,983)**	**Percentage**
Disability status	**No**	2,588	92.4	**No**	2,714	91
	Yes	214	7.6	**Yes**	269	9
Number of difficulties (*a lot of difficulty* or *cannot do at all*)	**0**	2,588	92.5	**0**	2,714	91
	1	162	5.8	**1**	194	6.5
	2	43	1.5	**2**	60	2
	3	6	0.2	**3**	14	0.5
	4	3	0.1	**4**	1	0.03

During Round 2, 3.7% of community members enumerated reported ‘a lot of difficulty’ or ‘cannot do at all’ in seeing, 1.7% in hearing, 4.0% in walking or climbing and 2.3% in remembering or concentrating (Table 7). The proportion was similar in both rounds.

Table 7: Description of Washington Group variables

	Round 1				**Round 2**	
Domain	**Response**	**Frequency (N=2,802)**	**Percentage**		**Frequency (N=2,983)**	**Percentage**
Vision	No difficulty	2,622	93.6		2,769	92.8
	Some difficulty	79	2.8		104	3.5
	A lot of difficulty	100	3.6		107	3.6
	Cannot do at all	1	0.04		3	0.1
	No difficulty	2,706	96.6		2,873	96.3

	Round 1				Round 2	
Hearing	Some difficulty	58	2.1		59	2.0
	A lot of difficulty	37	1.3		51	1.7
	Cannot do at all	1	0.04		0	0
Walking	No difficulty	2,686	95.9		2,707	90.8
	Some difficulty	56	2.		157	5.3
	A lot of difficulty	59	2.1		118	4.0
	Cannot do at all	1	0.04		1	0.03
Remembering	No difficulty	2,623	93.6		2,792	93.6
	Some difficulty	116	4.1		124	4.2
	A lot of difficulty	61	2.2		67	2.3
	Cannot do at all	2	0.1		0	0
Communication	No difficulty	2,772	98.9		2,969	99.5
	Some difficulty	22	0.8		7	0.2
	A lot of difficulty	8	0.3		7	0.2
	Cannot do at all	0	0		0	0
Self-care	No difficulty	2,789	99.5		2,973	99.7
	Some difficulty	5	0.2		3	0.1
	A lot of difficulty	7	0.3		6	0.2
	Cannot do at all	1	0.04		0	0

The audit enumeration was not done in the same community during Round 1 and Round 2 (Table 8). During Round 1, disability was absent in Tougyankrom Unit 1 (0%) and Kaakra Akura (0%) but in Benkrom the prevalence of disability was 13.6%. The distribution of disability between the communities was uneven during Round 2 enumeration, with lowest prevalence reported in Kaakra Akura (0%), and the highest in Adaa Unit 2 (18.6%).

Table 8: Distribution of disability per community

	Round 1				**Round 2**		
Community		**Frequency (n=214)**	**%**			**Frequency (n=269)**	**%**
	Nkwakyire Unit 2	8	7.4		Adaa Unit 2 (TS)	33	18.6
	Benkrom	143	13.6		Benkrom (KN)	162	12.9
	Tougyankrom Unit 1	0	0		Nsuta (TS)	25	8.2
	Ankaase Unit 1	62	8.4		Derma Unit 1A (TS)	43	6.3
	Adomano	1	0.2		Adomano (KN)	6	1.4
	Kaakra Akura	0	0		Kaakra Akura (KN)	0	0

Remark: As explained in the data management and analysis section, uni and multi-variate relationships between explanatory variables and the outcome of interest (having received treatment or not) was just performed on Round 2 enumeration because the interest variable (having received treatment or not) was absent in Round 1 data base enumeration.

Univariate and multivariate associations with the treatment status (Round 2)

Table 9 shows the association between the district, sex, age, disability status and treatment status. Community members in the three villages in Tano South were four times more likely to have received treatment than those in Kintampo North OR=3.9; 95% CI= [3.1- 4.8]. Older people (>50 years) were 2.2 times more likely than younger people to have received treatment OR=2.2; 95%CI= [1.6- 3.1]. People with disabilities were seven times more likely to have received treatment than people without disabilities OR=6.9; 95%CI= [3.8-12.7]. There was no difference between men and women with regard to treatment status.

Table 9: Univariate association with the treatment status

		Treatment status		Odds ratio	P
		Yes n (%)	**No n (%)**		
District	Tano South	1,051 (90.7)	108 (9.3)	3.9	<0.001
	Kintampo	1,303 (71.4)	521 (28.6)	-	
Sex	Male	1,150 (79.4)	298 (20.6)	1.1	0.510
	Female	1,204 (78.4)	331 (21.6)	-	
Age – binary	< 50 years	2,016 (77.6)	582 (22.4)	-	<0.001
	> 50 years	338 (88.5)	44 (11.5)	2.2	
Age – groups	≤15	835 (77.3)	245 (22.7)	-	<0.001
	16-39	943 (76.3)	293 (23.7)	0.9	
	40-49	238 (84.4)	44 (15.6)	1.6	
	50-59	150 (89.3)	18 (10.7)	2.4	
	60+	188 (86.6)	29 (13.4)	1.9	
Disability status	No	2,096 (77.2)	618 (22.8)	-	<0.001
	Yes	258 (95.9)	11 (4.1)	6.9	

Multivariate association with treatment status

Following mutual adjustment for the effect of each other variable, Table 10 shows the independent associations of the three variables with treatment status. After adjustment, people from Tano South were four times more likely to receive treatment than those from Kintampo North (95% CI 3.2; 5.0); those over the age of 50 were 1.8 times more likely to receive treatment than those who were younger (95%CI 1.3- 2.5); and people with disabilities were 6.7 times more likely to receive treatment than those without disabilities (95%CI: 3.6- 12.4).

Table 10: Multivariate analysis with the treatment status

		Treatment status		**95% CI around OR**	
		Odds ratio	**P**		
District	Tano South	4.0	<0.001	3.2	5.0
	Kintampo North	-	-	-	-
Age – binary	< 50 years				
	> 50 years	1.8	0.001	1.3	2.5
Disability status	No	-	-	-	-
	Yes	6.7	<0.001	3.6	12.4

4.4 Response to evaluation questions

The following section outlines responses to the evaluation questions contained within the Evaluation Plan (Appendix 4). Main findings are presented under each respective area.

4.4.1 Overall question

The first question contained in the evaluation plan is:

“How does the data collected from this project compare with existing data on disability available for the project, and what may explain the differences?”

Little data exists on disability in Ghana, although several recent surveys have included questions on disability and the evidence base is now expanding. Although the 2017 Maternal Health Survey run by the Ghanaian Statistical Service are using the Washington Group Questions, the results are not yet available and will only be asked to women aged 15 to 49 years.

The 2010 census[iv] asked household heads to answer whether anyone in their household had “any serious disability that limits his/her full participation in life activities (such as mobility, work, social life etc.)?” If they answered yes, they were asked in which categories: a) sight b) hearing c) speech d) physical e) intellect f) emotional g) other. The Brong-Ahafo region (where our pilot took place) reported a prevalence of 2.3% compared to national average of 3%. This equated to 54,038 people with disabilities in the region, 33% of whom had sight impairments, 28% physical, 21% emotional, 17% hearing impairments, 17% speech, 16% intellectual and 9% other. 41% of people with disabilities had more than one impairment. In the Kintampo municipality, 2.6% of the population (or about 3,000 people) were reported to have disabilities. In the Tano South district, 2% of the population (or about 1,600 people) were reported to have disabilities. Data collected from the second round of the MDA, in particular, is similar to that collected in the 2010 Census in both districts.

The Multiple Indicator Cluster survey (MICS) undertaken by UNICEF in 2006 (5) which used the Ten Questions Questionnaire (6) to identify childhood disability, found that 16% of children aged 2-9 years have at least one form of disability. Little detail was reported on geographic variations and adult disability was not investigated. The target population of this survey does not compare well to that of our pilot and so it is hard to compare the data from the two sources, although the results of the MICs seem considerably higher than those of the pilot MDA data

4.4.2 Expectations

Main findings

- Very little data on disability was available in the area prior to this project
- Participants identified many ways that disability data could help with MDA and other development initiatives

Response to related evaluation questions

A. What are the views of implementers and policy/decision-makers on the data currently available to them related to People with Disabilities and their access to projects, and how do they think it can be improved?

Prior to the pilot, very little data was collected on disability during the MDA and it was limited to noting people who were blind, those with elephantiasis and those who could not walk. There was no methodology behind the data collected; rather it relied on the CDDs' own perceptions.

> *[…] there were no guidelines… there was no checklist to be applied, it's just the people's own perception and feeling and say this person is saying he is blind… maybe he has not asked the person himself or if he cannot speak, maybe somebody close to him [###] to classify the person."* (Disease Control Officer_15_ Derma sub-district)

B. What are the expectations of implementers and policy/decision-makers of a data collection system that disaggregates project data by disability, and how do they envisage it impacting on their decisions/work?

At the end of the implementation process, project implementers said that this project had helped them to identify the number of people with disabilities, which they felt would help in planning activities for people with disabilities.

> *"Because you will be able to know the number of people in the community, so budgeting for the community, drug, logistics and other things, you would be able to say this is the number of people I will be attending to with this quantity of items."* (Interview 2_health workers_Kintampo)
>
> *"In terms of planning, for there were some people who were not considered but now are considered in the MDAs."* (Interview 3_health workers_Kintampo)

C. How do implementers and policy/decision-makers understand the issues around the accessibility of people with disabilities to projects, and how do they see data as playing a role in accessibility?

Project implementers mentioned a number of expectations around the pilot disability data project, including that the project was expected to identify people with disabilities, types of disabilities and geographic distribution of people with disabilities in sub-districts. There was an expectation that the data would help in planning interventions, future programmes, distributing items (e.g. mosquito nets) in communities, and measuring service patronage as described by some participants.

> *"Ok, at our level we will now know that this number or percentages of population are disabled or have some form of disability and so in designing any health intervention, you will be guided by that. So if there is intervention, we are sharing mosquito [ITN], we know*

people who [have a disability] then deliberate effort will be taken to get those services at their doorstep." (Disease Control officer_ 15_ Derma sub-district)

Some project implementers felt that the data collected could be useful in strengthening service delivery. The data would help determine treatment coverage for people with disabilities. The data could be further disaggregated by gender and compared with the general population.

"W*e are no more going to look at just the coverage… we are going to look at people with disabilities, male and female, prevalence of disability, how many people with disabilities that actually access the MDAs and those that missed it, and that will inform future policy."* (Disease control officer_ 15_ Derma sub-district)

Some project implementers further noted that the data from the project is expected to help in planning support services, creating accessible environments and making services inclusive for people with disabilities. The data is expected to inform stakeholder groups - including government and NGOs – which support people with disabilities.

"My facility is having steps so now that I have been able to get data that this percentage cannot climb steps, I will make a free walk-way for them so that in case they are even coming with wheels or any assistance, they will be able to come freely to the facility." (Male health worker_ Dawadawa health centre)

4.4.3 Training and sensitisation

Main findings

- Participants reported little knowledge or understanding of disability prior to the project.
- Participants enjoyed the training and reported increased knowledge and understanding of disability and the issues surrounding it.
- Participants reported the WGSS to be a completely new approach to them but generally found it useful.
- Participants appreciated the stigma-free way the WGSS questions are formulated as it helped remove embarrassment.
- Participants reported improved communications with people with disabilities as the WGSS was generally well-received by communities.
- Health workers perceived that the disability questions increased the likelihood of community members engaging with CDDs and felt it may have increased the number of people accepting treatment compared to previous rounds of MDA.
- Participants expressed new awareness of barriers faced by people with disabilities and the need for services and infrastructure to be accessible to all.
- Health workers and CDDs stressed the importance of regular training and monitoring to ensure quality data.

- Financial constraints around CDD recruitment and training impact data collection generally, including disability data.
- Challenges around data collection and recording accuracy remain, though strengthened monitoring of CDD activity would be useful.

Response to related evaluation questions

D. How useful is the definition of disability provided by the Washington Group to implementers and policy/decision-makers and how does it complement their own understanding of disability?

Training on disability identification using the Washington Group questionnaire had a very positive impact on participants' knowledge and attitudes. During the second phase of this project, participants described how using the WGSS had improved their knowledge of disability. Participants said that previously they would have identified a person with a disability by using their own judgement, for example if someone was obviously blind or had difficulty walking. They said that the WGSS training had broadened their knowledge of disability. The CDDs understood the concept of asking people about the levels of difficulty they faced and reported being clear about asking people the questions, rather than making judgements about their disabilities based on physical appearances.

"Personally, it has broadened my knowledge concerning persons with disability. First we could see a blind man and someone who could not walk and we refer to them as disabled, but because of the project I have been able to see other people with disabilities not only the blind and people who cannot walk. It has also helped me know that certain people with disabilities can perform more in some areas than even people without disabilities." (Interview 1_health workers_Kintampo)

"[…] even if we see the person, see that he has problem with the leg [physical deformity] we have to ask the person, we have to ask the person that, "please, with your leg are you able to walk?", or even when he mentions that he is able to walk, ask further that, "please do you have difficulty…?". The level of the difficulty will let you know that the person has a problem." (CDD_15_ Derma)

E. How do the staff collecting/analysing the data understand disability and how can the training best orient them to the definition provided by the Washington Group?

All participants felt that the Washington Group approach to measuring disability differed from previous definitions used in Ghana. They understood that the Washington Group defined disability using the functional model to understand the limitations experienced by clients. Generally, this was thought to be a positive approach and project implementers, for instance, felt that the questions helped to reduce stigma and discrimination against people with disabilities.

"The differences are that with the other definition of disability they are limited, so when we are providing health services we limit it to those aspect alone but with the broader [WG]

definition of disability based on the functional definition we can capture more people who are with such problem so that we can also deal with them as well…" (Female health worker 03_ New Longo health centre)

Project implementers, and CDDs in particular, expressed the importance of training in shaping their perception of disability. Project implementers specifically felt that the training had helped to educate them about the religious or cultural beliefs that may promote the discriminatory attitudes and stigma they associated with disability prior to the training.

"I got to know that disability should not be associated with evil and then the stigma attached to it all should be taken out… not to see the individual who is disabled as evil." (Health worker 02_ Dawadawa health centre)

Participants felt that a functional definition of disability helped them contextualise disability issues as being about participation within society, and not simply limited to an individual's physical impairment. CDDs understood that the functional model explains disability as a limitation which could be remedied with appropriate support, as opposed to the medical model which describes disability as a sickness.

"In society they were neglected but right now I [am] made to understand from the WG definition of disability that they are part of the society and there is no need for us to stigmatise against them. We have to allow them to participate in whatever we are doing in society because there are certain things they can do more than those we think they are not disabled." (Female health worker 03_New Longo health centre)

"The medical model… [###] when we look a person and say that this person is sick and that he cannot do anything, but the functional model tells us that for instance if someone who is blind we may think that the person is blind but if we provide some aids [assistive devices] to assist the person he can play football or do something." (CDD_1_ Derma)

A few CDDs felt that the language of the WGSS made them easy to use. They described the questions as preventing the anger that may stem from asking directly if someone is disabled, which may be perceived as insulting. This was realised when questions were asked in ways like "do you have difficulties in terms of walking or climbing?" or "do you have any difficulties seeing even if wearing glasses?" Specifically, a selection of the CDDs added that the best approach in getting the right response was asking questions following the right procedure and in a respectful manner. CDDs and their supervisors agreed that asking questions in a harsh way would not yield the right response.

"The Washington Group of questions has now made it simpler and then it also goes in such a way that the one who receives the questions wouldn't become angry but will be able to accept it. Like you ask, "do you have difficulties in terms of walking or climbing?",

> *or “do you have any difficulties seeing, even if wearing glasses?”, so it has made it more simple.*” (Health worker_02_ Dawadawa health centre)

Although many CDDs felt they had a good understanding of the WG concept during training, their supervisors noted that this did not always translate well to the data collection, especially for the response categories that determine disability. Some health workers felt that the training should follow up with a series of practise exercises to examine whether volunteers understand the WG concept.

> *[…] you may think he is OK with everything but when you take him to the field, he will do something different altogether. So it is very important that after we are done with the training we take them in series of practical… take some of us, they should sit down with us and ask the questions, the questionnaire, and we will get to know that they really do understand what they’ve been taught or they done other than that they will go to the field and do something different altogether from what they learnt here…”* (Health worker, 1)

One community health worker said that it was challenging for some CDDs to understand the difference between “yes some difficulty” and “yes a lot of difficulty”. This was expressed as follows:

> *“I think it’s the same thing just as my colleagues has said because for the volunteers to understand the difference between “yes, some difficulty”, and “yes, a lot of difficulty”. It was challenging for them… there were some that you could see that the difficulty wasn’t that much… but yet still they will go ahead and make it a lot of difficulty. So such people are all counted as people with disabilities but in actual sense they are not disabled.”* (Community health worker, 5)

Overall, some health workers expressed the need to strengthen the training of CDDs, specifically by increasing the time allotted and allowing more time for practise and role-play. The health workers felt that the current timeline was limited to adequately prepare the CDDs, many of whom were traditional volunteers with low levels of education. One health worker noted that some volunteers did not have enough understanding of the WG questionnaire and adopted “on-the-spot” training during field supervision to enhance their knowledge.

> *“[…] so I actually had problems with those volunteers who didn’t have enough understanding of the questionnaire because I remember some households were already administered with the questionnaire… before they had the problem and I got there, the questions or my understanding of what they were talking to me about wasn’t what they were supposed to do… so I had to take them through some sort of on-the-spot training for them to continue…”* (Health worker, 9)

F. How does orientation on disability issues affect the way staff interact with project clients/ patients with disabilities or impairments?

During the second phase of this project, participants described how learning about the functional definition of disability changed their perceptions regarding drug distribution. It helped them understand that a disabled person can take drugs in the same way as people without disabilities.

"it has helped us because at first we didn't know that disabled persons too can take the drug but now we include them. But at first, when you see a disabled person, you just pass them by but after the training, we have noticed that disabled people too can take the oncho medication to help him/her." (Kintampo Focus group 1)

"It was from this project that we realise that it's because of persons with disability that even some of us able person gets some of these medicines to take. Also, initially during drug distribution exercise, persons with disability were not included in the process. But now we separate them and treat them better. And these are some of the benefits." (Kintampo Focus group 3)

At the end of the MDA, project implementers and CDDs reported the importance of the training before going to the field. CDDs felt that the training has helped them in the identification of people with disabilities. It also improved their understanding and changed their perception regarding disability.

"The training really helped us. Sometimes on the field you would see a household and you might not know there is a person with disability in there. But with the training we are able to identify these persons with disability and provide them with the needed assistance." (Kintampo Focus group 3)

During this second phase, CDDs reported a change and improvement in their communications with people with disabilities, and that people with disabilities felt more able to seek support.

"It has a lot of effects, first when we go about registering persons with disability, it was difficult for persons with disability to give you their names. But since they began realising the benefits, drug distribution and care the project offers, persons with disability were ready to mention their names and be enrolled on the project. Some even trace us to our house to be registered because of its benefits." (Kintampo Focus group 3)

Some project implementers felt that the training has made them aware of negative words that could be offensive to people with disabilities, and has in particular educated them on how to approach or ask questions about people with disabilities.

“Let us say we shouldn’t use certain negative terms for those people which will impact negatively on them, because if we try to use those negative terms then we are just trying to stigmatise the disabled. So now instead of using such words for example the ‘39/40’ [local name for people with one functioning leg] for someone who is a cripple, now we should try to use positive terms to describe them.” (Disease control officer_ Kintampo municipal)

Project implementers and CDDs further expressed that the training has helped them understand the need to recognise people with disabilities in society, especially in public gatherings and during the construction of roads and buildings.

“[…] the training has made us understand that when there is any gathering, we should look at where people are disabilities are located, when we organise gathering near people with disabilities, they can also come there, and in everything that we do, like constructing roads, building a house so that wherever we meet they can also come around.” (CDD_ Derma sub-district)

G. What are the views of implementers and project managers on the sensitisation/training provided to them, their staff and data collectors and how do they perceive it has affected the way they conduct their work?

H. How are staff analysing the data and how can training best orient them to summarise and analyse data in a way that is useful for them?

During the second phase of the project, when CDDs had a better understanding of the WGSS, health workers reported an impact on the number of participants compared to the first phase.

“The volunteers took their time to ask all the questions. This year the number of people interviewed had increased compared to last year where they register people without asking questions on this disability, so that you could see that there were some questions they skip, but this time - because of the disability data - they made every effort to enter every household to administer the questionnaire that was supposed to be administered. So in that case it has increased the number of people we administer the drugs to this year as compared to last year.” (Interview 1_health workers_Kintampo)

Health workers (10) described the various ways that the training has improved their knowledge and understanding. They felt that the training package and mode of delivery was useful and built their capacity in knowing and dealing with people with disabilities. Participants described how they expected to improve data quality in the data collection process.

“I see the training as very useful… very knowledge impacting and in fact it has being very resourceful in terms of knowledge acquisition… so it will have the impact during the data

collection when I get to the field being the supervisor with the community volunteers… I think with that it will also help to improve the quality of the data within the district." (Health worker 05_ Kintampo North district)

The health workers commented on some challenges with registration and documentation, especially during monitoring and supervision visits. Two health workers discovered that the questions were not being directed to the right person. Some CDDs were asking the WGSS to household heads or landlords on difficulties experienced by all the household's members.

"[…] on my first round to supervise what was going on in the field, I realised that the volunteers were asking the landlords and the landladies about individuals as to whether they have challenges [difficulties] hearing, walking, self-care and all those things. So when I detected that, then I have to start from community one to the last community to tell them that they have to administer the questionnaire to every individual…" (Community health worker, Number 9)

Even though CDDs reported being confident with the WGSS, some health workers noticed difficulties during registration, especially with writing. Some health workers suggested that CDD recruitment needs to focus more on the literacy of the volunteers. At the end of the first implementation phase, health workers also expressed the need to recruit more knowledgeable health professionals in order to collect data on disability that is more accurate. Health workers felt that even with more training, they may still not get accurate data. One community health worker mentioned that there were some challenges with the compilation of the report from CDDs. Another, for instance, expressed that there was inconsistency between the summary report and the corresponding WGSS responses in the tally sheet. This was expressed as follows:

"*These are some of the challenges, they were too few and we have some volunteers who could not write well. I am thinking overcoming this would mean we recruit more volunteers in future if we are to continue this project and look for people who can probably read and write very well to administer the questionnaires as far as the disability data is concerned."* (Interview 1_health workers_Kintampo)

"The major challenges were the registration by the CDD, which for most of them in terms of education were limited and they still have the perception of disability as people who cannot do anything at all. So to improve upon this challenge, as I said earlier, is to recruit health professionals who have knowledge and would be able to asses for people with disability. Yes please… for the training, it can be done. But looking at their level of understanding with more training, we might still not get the accurate data we want. But if we add the professionals and health workers we will get the accurate data we want."(Interview 3_health workers_Kintampo)

"…you open [the report] and you could see some with disability but you go to the Washington questionnaire and there is no indication like that! … the person wrote with

disability and you check and there is nothing like that… so you ask yourself where is this coming from? So that was some of the challenges." (Community Health worker 2)

After the implementation process of the second campaign, some health workers suggested that more CDDs, as well as more supervisors, should be recruited in order to reach many communities and put in place a good follow-up.

"Well, for the part of the number of volunteers to be increased, I don't know whether it's a financial problem, probably it depends on what we are giving to the volunteers and the number of volunteers given to you. Funds is part of it, if the funds could be increased then we can also increase the number of volunteers to take part in the registration as well as the number of supervisors." (Interview 1_health workers_Kintampo)

I. How often do staff require refresher trainings or support to maintain high-quality data collection?

General MDA refresher training is delivered twice every year. There was no specific month designated for the refresher training, but it is normally delivered every six months - first at district level, then followed by sub-district level. The community volunteers are trained together, but additional time is allocated to new volunteers. Some project implementers felt that the training could be delivered more frequently than twice a year.

"It should be quarterly because it is very interesting and the more you are trained on a particular topic, the more you get experience and the more you also go out there to bring information and meet the challenges and the more you get the challenges, then you also get experience!" (Community health nurse_ AsanteKwa CHIPS).

Some project implementers mentioned delays in the release of funds, which affected the timeline of the project.

"I think the late arrival of funds affected the timelines. With the second round, look at the time we did the registration and the time we did the drug administration; the gap. So, we had to go back and train volunteers on the update of the register and that one too took some resources like time, energy and funds." (Interview 4_health workers_Kintampo)

One of the health workers mentioned that most CDDs could not attend sub-district level training, which resulted in follow-up training for them within the communities. This delayed the data collection process, as described by a community health worker.

"*You see we had a situation where most of our volunteers could not attend the training so in fact due to the scattered nature of the sub-district communities, we had to take our time* *to go to most of the communities that could not make it for the training and also train the volunteers. I think that one has delayed the process a bit."* (Community health worker, 3)

Some project implementers (7) expressed the need for refresher training specifically for the disability data collection. It was felt that training would help health workers and volunteers to understand disability and gain experience in collecting disability data. Some project implementers added that training would be particularly useful for new health workers and community volunteers. After the second campaign, some health workers also suggested that long intervals between training were detrimental to their knowledge, and that training should be repeated frequently.

"Just as I am saying I have not done [the training] before, it may happen that a colleague has also not done [the training] before. I know that in the following year, [the training] will help someone who has not done some before and does not understand disability, it will help such person to also understand." [CHN community health nurse_ Derma Health Centre]

"On the training too, I am thinking that the period for the training sometimes should not be very short. Sometimes right after the training, the project implementation starts. It should not be like this, there should be some interval time so that people who don't understand something can ask them before going to the field to implement them." (Interview 1_health workers_Kintampo)

After the implementation process, CDDs also expressed the need for information materials to refer to after the training.

"I think it would be good if we get refresher training once a while to keep remembering the things we learnt, or even if you get us a pamphlet to read." (Kintampo Focus group 1)

At the end of the second distribution campaign, health workers (4) reported that repeat training was very important because it allowed them to improve their understanding of some concepts. Participants describes the importance of training as follows:

"Because we wanted to increase the coverage as far as the MDAs is concerned. We saw some little mistakes during the first round, and this time round we have to intensify the training to avoid certain mistakes we did previously regarding the disability data." (Interview 1_health workers_Kintampo)

Some project implementers and CDDs made suggestions on the best ways to strengthen the training in future. One project implementer suggested the need to extend the training to two days to help participants better understand the concept. Another project implementer expressed the need for the programme to consider CDDs who work in communities outside their residency. This is expected to help them accomplish tasks within the stipulated time and therefore achieve high-quality data.

"On the training, if the number of days for the training could be increased it would help." (Interview 3_health workers_Kintampo)

"[…] you should also consider those who are outside a certain community [CDDs who are not staying in the communities where they work], how the person will work effectively and how the person will take time… this thing it needs time." (Health worker_ Derma Health Centre]

4.4.4 Process and tool

Main findings

- Despite improvements in the second round, participants reported ongoing issues with data quality.
- All participants felt that MDA during the rainy season was difficult and should be avoided if possible.
- Existing issues with CDD motivation, retention and recruitment still remain.
- CDDs discussed that MDA generally was time consuming for community members and themselves, and that the additional questions compounded the problem.

Related evaluation questions

J. How can the MDA process be best adapted to collect quality data on disability data without creating a delay in drug delivery, and is registration the best time to collect disability data? (How does the appropriate data collection methodology impact on the quality and timeliness of the data available to implementers and policy/decision-makers?)

Health workers expressed their views about the quality of data obtained from the project. Some community health workers perceived that the data is of good quality because training, monitoring and supervision were provided to strengthen the data collection process.

"…we went through the training and when I went to the field for supervision and monitoring, I think the response I had, some of the observations I made [made] me believe that the data is of quality." (Municipal disease control officer, Kintampo)

"There is no doubt that the fact that the data we collected is of quality because… you have to go and you have to sit with the person one-on-one, the person comes out with everything, the kind of disability that the person has, so here I don't think there is any information that we collected that is not true. So the data is of quality." (Community health worker, 1)

Many health workers reported that the introduction of disability data collection in the MDA resulted in increased coverage and helped to reach marginal populations.

> *"Data collected has impacted or is of use to the MDAs and health delivery at large. Because this time round the disability data has helped to increase the coverage as far as drug distribution is concerned."* (Interview 1_health workers_Kintampo)

One community health worker had a contrary view and felt that the limited number of supervisors and short duration of the training could compromise the quality of the data, hence they rated the data quality at around 80-90% as described in the following quote:

> *"[…] I will rate… that in terms of quality I will rate it 80-90% because I was lucky that most of my volunteers were trained teachers and some too were not trained teachers. The duration of training was too short for them to understand the questionnaire before going to the field to administer it. And then one challenge that also came out has to do with the supervision because I realise that most of the volunteers had problems and the supervisor is only one, so it was actually difficult moving from community to community, because you cannot go every day and it's not all the time that you will be to get them. And then our network too is not strong, they will call and they will not get you so time they do the work and they have to stop until you come, they cannot continue…"* (Community health worker, 9)

In order to improve data collection, specifically at registration, health workers suggested that data should be collected during the dry season (Harmattan).

> *"The second challenge is some of the community members you go and you won't meet them. This area is a farming community, and most of the time, they go and stay on the farms especially during the raining season. So, if registration could be done during the Harmattan season, which is when most of them are around and do not sleep on their farms."* (Interview 3_health workers_Kintampo)

It seems that a number of people with disabilities who were registered by the CDDs were not present when they returned with the drugs.

> *"When we were distributing the drug, we couldn't capture some of the persons with disabilities who were absent. We registered them, but we couldn't reach them."* (Municipal disease control officer, Kintampo)

K. What are the cost and time implications of disaggregating data by disability for partners? Is the approach developed sustainable?

Project implementers mentioned some management-related challenges with the inclusion of the disability data collection, as well as some related to delivering the MDA more generally.

Two community health workers experienced some miscommunication relating to payment ("per diem") and changes in the number of drugs to be distributed to clients. CDDs were informed to distribute only albendazole during the treatment phase, though they were informed during training to distribute both albendazole and ivermectin as described by one participant.

> *"[…] it's not pertaining to the ivermectin but the albendazole… you know we started with them, we trained them and we told them that they will be given two drugs thus they will be distributing two drugs but at a point we were told that they shouldn't go ahead with the albendazole so it brought a lot of challenges."* (Health worker, 4)
>
> *"Yes, that they started the registration but the day that they are doing the distribution, one of them was saying that they should pause the whole exercise because we are supposed to give them their per-diem for the registration before they continue the distribution!"* (Municipal disease control officer, Kintampo)

A selection of the participants described the need for increased financial resources for social mobilisation and sensitisation. This was attributed to improved social mobilisation and communication, especially when the disability data was introduced, as described by one participant.

> *"Resources for social mobilisation should be increased… we were given 100 Ghana [cedis] from the MDAs for social mobilisation, Sightsavers came out and added additional 200 for social mobilisation that has gone to reach the six information centres within the sub-district and then to also inform the chiefs. We've been able to do so I think the support has increase our coverage or reach as far as social mobilisation and communication is concerned."* (Disease Control Officer_ 15_ Derma sub-district)

One of the health workers expressed the need to increase CDD financial incentives. During the post-MDA interview, some health workers identified the low motivation of CDDs as a barrier to the improvement of the implementation process.

> *"We know our CDDs, most of the time it's about motivation; if we motivate them they do the right thing for you because they have other things they are supposed to attend to but because of the work we give them if we are able to motivate them I think will be good in terms of maybe wellington boots and others."* (Interview 4_health workers_Kintampo)

Two CDDs felt that despite the success of the training, there is the need in future to provide a certificate for participants. One CDD, in particular, felt that the current t-shirt given to volunteers is not enough for their communities to recognise them as conducting official Ministry of Health work and suggested the need to also provide an identity card to support their work.

> *"[…] please the training has been successful but it seems the CBS [community based surveillance] has done the work for very long but the t-shirt alone cannot help to recognise him as a CBS because everyone can borrow the fellow's t-shirt… If you can't provide a certificate at least an ID card [identity card], I think that will be OK."* (CDD _Derma sub-district]

Insufficient numbers of supervisors may also have impacted the quality of data collection and some project implementers suggested the need to increase the resources available for better supervision.

Some CDDs also reported a low level of supervision in their communities that may cause certain types of mistake.

> *"[…] you will go there and one supervisor supervising the whole of Gulumpe… meanwhile we have other duties there… so it will be difficult for you… so the number of people should be increased and the number of supervisors should be increased…"* (Health worker, 8)
>
> *"There is community called Nkyenedie, truthfully most of the supervisors had not been visiting that community. The community is hard to reach, yet we go there but our concerns are not met when we report to them."* (Kintampo Focus group 4)

A few project implementers and CDDs requested the need for resources to support the MDA programme, especially with the inclusion of disability data. The resources included requests for pens and pencils for CDDs, motorbikes, bicycles, fuel and raincoats to support CDDs and health workers going to the field in remote areas and in poor weather.

> *"Please, the training has helped us to know a whole lot of things but what we will plead you is that now we are in a rainy season, as we are going about the book can even get wet. So, we will recommend that you provide us with a raincoat or wellington boots so that we can be protected when it is raining."* (CDD_ Derma sub-district)

M. How do the tools and guidelines developed specifically for this project fulfil their purpose and how could they be improved? (How does the appropriate technology, including hardware and software, impact on how staff are able to collect and analyse data?)

One of the health workers further described a challenging situation where volunteers were using sheets to represent households instead of the allocated boxes in the community tally sheet. Educating volunteers to correct these minor mistakes during monitoring and supervision visits delayed the process, as described by a health worker:

"Somebody will come and tell you that my book is finished. You will go and you see empty spaces on where we write the names but when you go to the tally sheet you see that they exhausted the tally sheet. So, because of that it delayed everything because I had to go round again and then educate them that a box is for a household not a sheet for a household." (Health worker, number 8)

Some CDDs expressed the need to address some other minor challenges with the community tally sheet. One CDD, for instance, suggested the need to have the community tally sheet to follow the register in one section. Another CDD further felt there is a mismatch in how the lines in the tally sheet have been arranged and suggested this should be addressed.

Some CDDs specifically felt that transferring the data from the community tally sheet to the register was time-consuming and required patience. Clients also perceived that the time to respond to questions was too long as they needed to visit their farms. Some CDDs felt that the process could easily make them angry, especially when transferring the data in the midst of family activities. CDDs expressed these as follows:

"There are some people after writing their names in the register… and you mention that there are additional questions to be asked… he will tell you I am going to farm so I do not have time to wait… that is also a problem." (CDD Number 15, Derma)

N. What extra burden does collecting the disability data place on the staff working with the data in terms of their time and taking them away from other duties?

At the end of the implementation process of the second round, CDDs said that although this project is a volunteer project, the supervisor expected sacrifices from them and asked the project leaders to support them.

"It's because the project is a volunteer project, so the project supervisors expect that you do make our own sacrifices to see to the success of the project. But ask the leaders to support us bit in this regard." (Kintampo Focus group 3)

CDDs and community health workers expressed that the addition of the WGSS made the work difficult and characterised it as stressful and time-consuming with an increased workload. Community health workers felt that the introduction of the disability data leading to fresh registration is time-consuming compared with previous exercises where registers were readily available. Participants commented on this as follows:

"I think comparing the delay this year and that of last year, looking at last year already we had the registers intact so you go in and you do the distribution and now we are doing fresh registration and questionnaire attached. So after registering, the number of times you need to spend on one person is roughly five minutes per head, so per head, per

household and before you move out of that, so that actually wasted a lot of time because of the fresh registration and the questionnaire." (Community Health worker 9)

"Looking at what we did previously… you know the Washington questions were not part of it so it made everything go well… somehow the volunteers were fast with what they were doing but since these questions came… they were somehow time wasting and other stuff… so I will say the questionnaire that came in brought some problems…" (Community Health worker 2)

"[…] I realised that with the addition of the questions, it was challenging for us… it made the work difficult… I think all the responses that we have presented confirms because for me […] the questions and the response category especially those who were having problem with hearing… they needed facilitator respondents to explain to them… I saw that it was challenging for the work." (CDD_ Derma)

"When it happen like that you develop anger… you are doing it and transferring it to the other end [transferring to the register], when you are doing it and your son talk to you, you can hit him if not careful or even you become angry when your wife talks to you. So that is the difficulty we experience." (CDD, Gulumpe community)

Some community members complained to CDDs that they did not see any benefit of the project, although they were expected to provide their information.

"My main challenge was that many people were complaining that we wrote their names and they were not seeing any benefits coming their way, so I explain to them that, before anything could happen it has to start small, also doctors don't [do] their things anyhow, secondly they know that no one builds a house in a day. They should be patient and the benefits would come." (Kintampo Focus group 3)

4.4.5 Community

Main findings

- Participants found the community sensitisation extremely useful for providing information on disability generally as well as on this project.
- Differing languages and norms of some ethnic groups impeded data collection.
- Some data collectors reported that older people and people of particular genders (this varied between data collectors) were more difficult to collect data from.
- Collecting difficulties from participants with communication impairments was challenging for data collectors and they required support from the individuals' family or friends.
- Some confusion was reported around certain questions, in particular those on self-care and remembering/concentrating domains caused confusion and - in some cases - anger from community members.
- Expectations from some community members may have exceeded what the project planned or was able to deliver.

Response to related evaluation questions

How well were communities sensitised to this project and how did it affect the implementation?

P. What are the views of implementers/project managers on the sensitisation provided to community stakeholders identified in the stakeholder mapping?

Sensitisation within the MDA programme follows a process involving community opinion leaders, health workers and CDDs. The process involves informing community opinion leaders (assembly members and chiefs) and is followed up with community gatherings such as durbars, the delivering of letters to religious leaders (churches and mosques), and various information sharing sources including the radio and community information centres.

Some health workers (3) further described that sensitisation could be strengthened through increased visits to community information centres and embedding it into sessions at the child welfare clinics (CWCs) and antenatal clinics (ANC).

At the end of the campaign, some CDDs suggested that communities should be informed prior to their visit, up to two weeks before starting the registration.

> *"When we are about to start the drug distribution, an announcement should be made for two weeks before we start the registration and the distribution, this will help capture everyone's data. With this, community members will have enough time to wait for the exercise before leaving for their farms."* (Kintampo Focus group 2)

Some CDDs further suggested that registration could be done regularly or that the period of registration could be increased.

> *"The time period for the registration process should be increased a bit. Some communities are far too big and the population in them are more. So consideration should be given to increasing the time for registration."* (Kintampo Focus group 4)

A selection of the health workers suggested that creating awareness amongst the public will help reduce the challenges that data collectors are likely to face, and will help to improve the uptake of the drug as well as ensuring data quality.

At the end of the second campaign, health workers said that the sensitisation process really affected the project positively. It made people much more open to discussing disabilities.

> *"The messages were carried across the whole community on whatever we were going to do, so they were alerted and it created awareness for the community members on the exercise that was going to be carried out. It made them come out and open out to really tell us the kind of disabilities they were having."* (Interview 2_health workers_Kintampo)

Health workers reported that sensitisation and training positively influenced the implementation process. The sensitisation strengthened their activity and positively impacted the number of people accepting treatment.

> *"The sensitisation affected the success of the MDAs positively, in the sense that as compared to previous years. This time it was strengthened; this time we did the sensitisation in churches and mosques which affected the coverage. If you even compare the number of people who refused in the previous years, it is greater than the number of people who refused in the current campaign, which is an indication that the sensitisation went well with the people or they understood what was said. So it has affected the success of the MDAs positively."* (Interview 1_health workers_Kintampo)

Was the project implementation affected by any particular community or sub-group norms?

Q. For data collectors based outside of health facilities: how do staff feel that community knowledge/attitudes/norms affect the collection of this data and do they experience more challenges in specific groups within communities?

Some CDDs (8) described challenges dealing with clients from different ethnic and language backgrounds. These challenges were experienced when dealing mainly with clients from the Fulani ethnic group. They do not understand the dominant languages spoken by the majority of the community members (Twi or Hausa). Females from the Fulani ethnic group often refused to participate due to the absence of their male partners. Other clients from the Dagate ethnic group perceived the questions as unnecessary. CDDs described these challenges as follows:

> *"[…] with the Fulani ethnic group I visited there three times, let me shorten it, when you visit there and the husband is not available, they will never talk, I have to go again but the place is also far so I came to even report [to the officer]."* (CDD_ Kumso area)
>
> *"[…] for example I have "Mo" ethnic background. If I use "Mo" language to talk to the people about this question it makes it simple for me but because after doing these people [ethnic group], I move to a different language group [ethnic group], the response becomes challenging. Especially with the Fulani ethnic group… unless you get help from their ethnic member who can understand you and translate the question for you… so it brings challenges to the work. For anyone who speaks the language you understand, the work becomes simple! For someone who doesn't understand your language, the work becomes challenging."* (Male CDD, Kintampo).
>
> *"I had such experience […] I met some ethnic groups called Dagate… they mentioned that if I am going to ask them questions about these unnecessary issues, then I should leave their house with my drugs."* (CDD_ Derma)

Some CDDs resolved these challenges by using translator support to explain questions to clients. These translators were relatives or community members from the same ethnic group. A few CDDs further described that some clients felt that responding to the questions could expose the limitations they faced to community members, and they therefore exhibited anger. This was described as follows:

> *"[…] some people ask whether we are coming to ask them questions about their problems [difficulties they face] to announce to other community members the kind of difficulty they experience! So when you ask them such questions, they become angry."* (CDD_ Derma).

A few of the CDDs described how some households were particularly obtrusive to data collection. These households suspected that the data would be used for monetary gain and this influenced their willingness to participate as described by a participant:

> *"[…] there are some when you visit the household, the people are happy to be asked those questions, but in some households they feel that you are registering to go and collect money so they will not answer the questions wholeheartedly. You have to suffer on the person… he may not answer the question directly so you have to go over and over before you get some report about him."* (CDD_ Kintampo).

Some CDDs expressed difficulties dealing with various age groups and gender. Two of them expressed that it was challenging dealing with the elderly population, especially clients over 50 years of age. CDDs felt that the adult population were able to answer questions well, it took them longer time to explain questions to those over 50 years of age before understanding was achieved. CDDs felt that dealing with this population was stressful. This was presented as follows:

> *"When I compare those whose ages are higher [elderly population] to the younger ones since they are elderly and have problem with their activities, it takes a longer time for them to understand. So when you ask the question, they have to wait for some time and ask you again before you explain again for them to understand… so they find it difficult to understand, so it is stressful dealing with such groups that the younger ones!"* (Male CDD, Kumso sub-district)
>
> *"[…] the problem we faced was that when you compare to children, male adults and elderly women, the adults are [more] able to answer the questions correctly than the elderly women of over 50s."* (CDD_ Kamokyi sub-district)

Five of the CDDs described some of the challenges in dealing with gender by comparing responses from males and females. The views were split among those who perceived females as hard to deal with and those who perceived males as hard to deal with. Two CDDs perceived women to be more difficult when responding to the Washington Group questionnaire. However, one perceived that it was difficult handling males and attributed this to them not knowing details about their children's ages or weights as this is perceived as a female responsibility. This was expressed as follows:

> *"[…] when you look through, the men make us suffer more… when you ask him how old is this son of yours, he will as a response go and ask the mother. It's the mother who has the weighing card that has the [child's] age."* (Male CDD, Kintampo)
>
> *"[…] when you look at it well it's the women who makes us suffer [challenging]… for all you know a certain woman, when you ask her the question, she will lift the leg to hit the ground for several times. When you ask, then she will ask again what did you say… when you continue she will say "Ok, I hear… let me think about it again", so you realise that the majority [of challenges] comes from the women."* (Male CDD, Sonoase sub-district)

Three of the CDDs felt it was challenging when dealing with clients with certain impairments, in particular those with difficulty hearing questions, those with multiple disabilities including intellectual those that were blind and those with speech impairment. For instance, CDDs had to repeat questions several times yet the client was still unable to understand. They contacted a facilitator respondent to complete questioning as described in the following quotes:

> *"[…] there are some people when you visit them and ask them the questions, they will respond and ask you what are you saying? You will repeat it for several times but it doesn't get well with him… you have to shout over and over before maybe you seek a facilitator to explain [the question to] the person."* (CDD_Derma).
>
> *"[…] I encountered such difficulty… I had someone who has intellectual disability and is blind… so when I visited him, it was challenging for him to explain things [questions] so we had someone as facilitator respondent before we were able to get information about him."* (CDD, Dwere Sub-district)

R. What are the experiences of staff in administering the extra questions to project clients, including the reaction of clients to being asked these questions and using the tools provided for the purpose?

CDDs expressed a number of challenges they met while asking the questions. Some of the clients were offended when they were asked questions relating to the "self-care" domain. Some clients exhibited anger, irritation and felt insulted, with others expressing regret in registering their names for the study. These challenges were overcome by explaining the question to the client further until they understood, and if this failed CDDs often left the house without asking the WGSS.

> *"[…] there are some people when you ask questions about self-care, they respond asking that 'please are you the one who puts my dress on me?'... you could realise that the person is getting irritated, so you have to exercise patience to explain further before…"* (CDD_ Derma)
>
> *"[…] the problem we had was related to the domain of self-care, I asked one man [client] about difficulty in self-care and he responded with 'did you come to meet me as a mad*

person?' He insulted me over and over so I got up and left… so asking those questions [self-care domain] was challenging." (CDD, Derma sub-district)

Other CDDs suggested that despite asking politely, it is possible that the wording of the self-care question may be intrinsically insensitive for some and should be reworded to allow for better community acceptance.

"[…] my colleague mentioned that he went to ask an elderly person and the person felt he was insulting him and dragged him off. If you ask anyone the questions in such manner, he will not feel comfortable. When we came for the training, we learnt that if you go and ask such questions, you should say 'please, do you require help before you are able to put up your dress or self-care?' But if you directly go and ask whether the person is able to dress or self-care, he will be offended with the question that you ask. So if we can polish it small, it will be helpful…" (CDD_ Derma)

This perceived difficulty was most evident when clients were asked questions relating to remembering and concentrating. This may be attributed to how the population contextualise and understand remembering and concentrating, especially people over the age of 50. One CDD did note there was some ambiguity in relation to this domain and expressed it as follows:

"[…] the domain about remembering and concentrating is one of the problems encountered, whenever you ask then they respond 'you know everyone have problem with remembering! Who doesn't have problem with remembering' … so that was very difficult for some of them." (CDD_ Derma sub-district)

Some CDDs also noted that although some clients responded as not having a disability, the CDDs felt it was obvious they did have limitations in certain domains, and that they may have been withholding information because of fear of discrimination. Of course, this also indicates a possible lack of understanding among the CDDs about allowing an individual to express the difficulty they themselves consider they face.

"… when you ask people about problems with [their] eyes or difficulty walking, it was difficult for them to respond that indeed they have this problem, but you the person doing the registration knows very well that this person is feeling shy or he doesn't was to expose that he has this condition [disability]. We try to advise that we are not going to expose their condition to someone elsewhere, it is doctors [project implementers] who have asked us to identify people experiencing that condition…" (Male CDD, Asareboi sub-district)

CDDs reported that asking the WGSS raised expectations among the community members for help related to difficulties they reported. In some cases, CDDs felt that the perceived availability of drugs or medicine, or even future help, encouraged clients to participate and had a positive effect on their willingness to answer the questions.

> *“[…] the majority felt that maybe if you ask questions about the eye, then you are going to provide glasses or you have something to help heal the condition [blindness]…”* (CDD_ Gyato Akuraa sub-district)
>
> *“[…] in the place I work, we also conduct [MDA] without [Washington Group] questions so what they were asking was that, “doctor, are you going to give us drugs this time around?”. I explained to them that it’s an organisation who are conducting this study… so if we identify that you are having any of the conditions [disability], we are measuring that we can help you! That’s what happened in my community, so their participation was encouraging.”* (CDD_ Boseama Sub-district)

A selection of CDDs expressed that clients expected specific help relating to money from the project and the district assembly. One CDD specifically mentioned that some clients wanted to know which help could be offered before responding to questions. This was expressed as follows:

> *“[…] there are some people you had to explain over and over… so even if you want to explain disability, he wants to know the kind of help you have for him. He even asks if there is help at the district assembly to support people with disabilities… he wants to know if indeed there is any help there before he will respond to your questions.”* (CDD _ Derma)
>
> *“[…] I asked that… they asked that these questions [many] have not been asked in previous MDAs... so are you coming to distribute money in addition this year’s MDA? I responded that no, we are not going to share any money but distribute drugs, but for us to know that the condition [disability] we are looking for, there is some in this community or there is none there… that’s why we are asking these plenty questions…”* (CDD _ Derma)

A selection of the CDDs reported that although clients understood the questions, they responded with different limitations from the domain asked. CDDs noted that some clients reported difficulties relating to general sickness, waist pain and stomach problems.

> *“They are able to understand, but there are some people who will go further to talk more about different sickness they have experienced and even mention the condition experienced by his sons and daughters… all because you have gone to ask about that question… they even complain about conditions faced by the unborn babies.”* (CDD_Derma).
>
> *“[…] there are some people who will not give you a response to the questions being asked but give different answers to the questions. For instance, if you ask ‘do you have difficulty seeing’, they will respond like ‘I don’t have any difficulty seeing but have stomach problems’… but there is no question about stomach problems, so it appears to disturb a bit.”* (CDD_ Derma)

Some CDDs (6) felt that clients understood the questions, yet had difficulty representing limitations based on the response category. CDDs perceived that some clients responded incorrectly and that maybe they did not understand the question correctly.

> *"[…] when you ask them they understand the questions but for them to represent the limitations, when you ask they say 'I have a lot of difficulty'… for instance when you ask about the eye, they say 'I am able to see but it itches me very often'…"* (CDD _Derma sub-district).

Some CDDs reported difficulties in clients' initial understanding of the WGSS. This required the CDDs to explain the questions further and often repeat them. Some CDDs attributed this to the fact that the questions were new to clients and resulted in a longer waiting time.

> *"[…] when I ask the questions I have to repeat, especially when you ask someone whether he has difficulty seeing even if wearing glasses… some asked what kind of glasses? And another few things, some people did not understand it well… you have to explain further before the client understands the questions well and answer you."* (CDD, Aboagyekrom Sub-district)

4.4.6. Data and next steps

Main findings

- Participants identified that additional questions could be integrated into MDA data collection activities to further strengthen services and support people with disabilities.
- MDA data is not currently collected from children under five years and pregnant women (as they do not participate in Ivermectin distribution) as well as from people with known mental illnesses. It was felt this omission was a weakness that should be addressed.
- Participants expressed value in the disability data collected and felt it should be scaled up throughout the country.
- Participants expressed an interest in sharing the findings of the project with other projects and health interventions.
- Participants felt that the data collected could have a wide range of uses including service delivery, planning and education.

Response to related evaluation questions

What additional data could be collected that would be useful?

S. Is the data provided by the data collection system to implementers and policy/decision-makers to the correct level of detail?

T. What data would implementers and policy/decision-makers like to have access to that remains unavailable?

One of the community health workers suggested that although the data is of quality, the exemption of children with disability under five years of age does not present a complete data set. This was presented as follows:

> *"There is a sort of discrimination in it, in the sense that we also have some people that are less than five years [of age] that were having [disabilities] but if you look at the data, it means they have been exempt, so I think that it compromises quality and inequality."* (Community health worker, Kintampo)

A few project implementers expressed the need for additional data to be collected. This was data relating to the occupational status of PWDs, the number of dependent children, pregnant women, children under a certain height and people with mental illness. One participant, for instance, noted that the WGSS is limited in capturing data on people who have severe mental illness, yet they are also a vulnerable group needing access to the programme.

> *"[…] Then I think the… that of the mind, they have been captured, it doesn't [###] the classification, what they want is to assess the mental faculty or the mind… I think there is limitation with respect to how… if somebody is completely mad…. [###]Yes, if you look at the MDAs, the mass drug, they are neglected… those targeted at the neglected tropical diseases, they are all neglected people that society is supposed to provide with shelter and those things but they are not, and they are the people who sleep on gutters and floors so they are exposed to mosquitos and those things that they can keep on transmitting… but I don't see how, so my [###] is that we extend the MDAs to those areas so that…"* (Disease Control Officer_ Derma sub-district).
>
> *"Sir, I think that what we collected is somehow okay but I think in future we add this data; we want to know the disabled [people] who are working and those who are not, so that if we have any support to give to them we will know where to prioritise and if we also know the number of dependents e.g number of children and others."* Interview 4_health workers_Kintampo

U. Are any aspects of this project being integrated into other projects?

V. How have implementers and policy/decision-makers integrated any aspect of this project into other project over which they have control, including disability awareness and collecting data on disability?

AA. How have data collection staff working on this project integrated any aspect of this project into other work over which they have control, including disability awareness and collecting data on disability?

A few project implementers suggested that the collection of disability data should be embedded to become part of the MDA programme. This will help obtain the number of people with disabilities and those receiving treatment. Some health workers felt that the data could be used to increase the MDA coverage.

> *"The project is very useful as far as MDAs is concerned, because in the first place it increased the number of people we used to cover. This time round more people, this time round we are able to see the number of people taking the medication and the number not taking the medication. So it's very useful in general to MDAs."* Interview 1_health workers_Kintampo
>
> *"Now that we know the number of disabled in our municipalities, we also have data on those who assess the MDAs services, it can serve us a baseline so that once we have that data we will see whether subsequent exercises the number is improving or its going down so that."* (Interview 4_health workers_Kintampo)

Two participants further added that the disability data could again be extended to other districts or nationwide.

> "*I think this training has been very helpful to myself because the way I perceived disability has been clear, that we shouldn't marginalise against them, we should always create room for them during our programmes especially in the MDA. We should create room for them because there is a saying that disability is not inability, they can also do what we think they cannot do... I think this programme is something though being piloted but if is extended to some district or even the whole nation it is going to help us. At least each district will have data on the number of people in that district so that in planning programmes, proper arrangement can be made towards them."* (Disease control officer_ Kintampo municipal).

At the end of the second phase, some implementers said that the disability data was now integrated within their MDA activities.

> *"Yes…it will still form part of the MDAs, the sensitisation, training, registration and data collection. We already have the name of the people but if we enter a house and someone*

is not registered, we would do the registration and still ask the questions. All the process would still continue when the project has ended." (Interview 1_health workers_Kintampo)

Many health workers reported that the implementation process was very helpful in the identification of the number of people with disabilities - this can be used to plan future activities.

"It is useful because it has helped us increase the number of people we were previously covering. When come to health delivery too, the data is used to plan for our activities for the future e.g. the number of women with disability, when get to know this data we are able to plan for them in terms of antenatal services because in this community, maybe two women are blind or have difficulties in seeing, and [if] such women are pregnant, any service that you need to give for her assistance has to be added." (Interview 3_health workers_Kintampo)

A few project implementers added that the training in disability data collection could be replicated in other districts. This would particularly help to identify the percentage of people with disabilities and understanding the Washington Group approach to measuring disability.

"*Because the other district might not know the WG definition of disability… they may define disability in their own way so once we know the definition of disability based on the functional approach, our data might be different from the data that is captured elsewhere in a different district."* (Health worker_ Kintampo health centre)

What other potential uses are there for this data or the lessons from this project?

W. How can lessons learned from this project be captured to implement this work in other projects and to share with partners and other organisations?

Two health workers expressed that the medium through which experience from this project could be shared with community members includes community information centres and radio talk shows.

Five health workers described the existing programmes that experience from this project could be shared with. The most cited programmes were the adolescent corner, Livelihood Empowerment Against Poverty (LEAP) and Intermittent Treated Nets (ITN) distribution. A health worker mentioned that it is expected that the disability data will help to make these programmes more inclusive of people with disabilities. Health workers commented on this as follows:

"I think there is this LEAP [Livelihood Empowerment Against Poverty] programme going on so most of the people who captured as people with disabilities from our area I think they can… when we share the information with some of the stakeholders, they can enrol some of them into the programmes… it will help them." (Health worker, 9)

"Anytime we are having a programme that requires that they should also be part, for example when we are having NIDs, we will know how we will just incorporate or how we

will just make sure that all those who are disabled will also be covered. When we have other programmes like distribution of ITNs and other." (Municipal disease control officer, Kintampo)

Two health workers noted that the data obtained from this project will be used in a variety of ways including for teaching, learning and research purposes. The available data could be used in future presentations to inform student's research as described by participants:

"[…] it will help us a lot through learning, teaching and for research purposes, at least we have the records now and per the demographic distribution when you are making a presentation, you can let your audience know that this is the number of people with disabilities that come from your place. You can still go further to tell them percentage wise, those who are hearing impaired and all those stuff…" (Health worker, 9)

"[…] I think this data will serve as a reference for us because it will teach us how and when to react, talk and how to work with people in the community, especially those with some disabilities. You will know how and [in which] manner to speak so that they wouldn't get hurt and also the required drugs they may need and also even if there is an occurrence of a new one, you will know how to go back to make subtraction and addition and that stuff…" (Health worker, 6)

Three health workers further expressed different ways of using the data obtained from this project, especially at the district levels. The emerging ways of using the data were to solicit support, to inform community health workers home visits and designing new facilities to become disability friendly. One health worker noted that the data will inform decision-making at the community level especially when iNGOs or any support group or association are embarking on projects for people with disabilities.

"[…] looking at the data we have, now we know that we have this number of people in our communities. Going forward … if you want to even bring them together for people to help such people you can say with authority the number of people you are dealing with, you will use that one to solicit for any [support] or whatever you want so that the people will help." (Health worker, 4)

"[…] most of the facilities in my area were previously not disability friendly but with the data at hand, facilities that are yet to be raised we could base on this data to make those facilities friendly to them." (Health worker, 5)

Other health workers also expressed that this data could be used to improve other activities or to inform people who need information on disabled persons.

"Well for the data we have already I think we have started using that data. So the data is already there and we count on it to do other activities we want to carry out. So we are not going to do away with the data so that if people want information on disability we can

provide and also use it to conduct other activities in the catchment area here." (Interview 1_health workers_Kintampo)

Some CDDs felt that this data could be used by the government or the NGO to support people with disabilities.

"It becomes useful, for instance, when a government or NGO wants to support persons with disability. We can provide data on them and since we know their location, the project would be successful. Even if they have special interest in cripples we can simply identify cripples from the community and get them to be supported." (Kintampo Focus group 2)

Five health workers promised to share findings and learnings from this project with stakeholders including the assembly members, chiefs, elders, unit committee members, health committee and various groups like women's groups. Participants felt that this will serve as an opportunity to use the available data to solicit support or advocate for people with disabilities:

"I think we've been having meetings with the stakeholders and the opinion leaders from the communities: the chiefs, the assembly members, the unit committee members. When we meet with them we can tell them these are the number of people we have in the communities, so when we are soliciting for support from them then we know how to go about it…" (Health worker, 8)

"[…] in my community I have [an] information centre so we can use that one to share the experience with the community and also meeting chiefs and elders of your community, the opinion leaders and then your health committee members. I think you will share it with them, there are women groups, yeah then even the adolescent corner, IYCF you can use that one, CWC, ANC services, PNC services, Family planning, FP services, you can use them, OPD…" (Health worker, 4)

One project implementer specifically expressed that this is an opportunity to share experiences and learning with the municipal family health committee and Kintampo Health Research Centre in their next meeting. They can use the data to lobby them on disability issues and for future collaboration on the programme as described by the participant:

"So especially Kintampo Health Research Centre, they are part so at the meeting when we raised issues concerning the disabled, their data and we are able to encourage them or we are able to lobby them, with time they can support us with our programme!" (Municipal disease control officer, Kintampo)

5. Discussion

Overview of results

The results presented in this report illustrate a variety of successes and challenges within the pilot DDD project. Stakeholders generally report highly positive impressions of the pilot and its results both in terms of how it has addressed existing issues within the MDA project and how it has raised awareness of disability among the communities and health care workers.

The data collected supports, to some extent, the feeling that the project has increased the number of people registered by CDDs and accepting treatment - the ultimate aim of the project. On the other hand, the data is not conclusive and questions about its validity remains. It is also not clear whether the resources applied to the pilot would make the sustainability of the activities prohibitive without external donor support.

It is suggested that larger scale evaluation is required to ascertain the impact of the intervention, preferably with control areas.

Uptake of treatment

In Tano South, 22,572 people were registered in Round 1 in 39 communities and 21,982 people were registered in 37 communities during Round 2. The number of people registered in the first round is slightly higher than that of the second round; this is due to the difference in the number of communities covered in each round. In the first round, 39 communities were surveyed while only 37 communities were surveyed in the second round. Note that the two communities belonged to nomadic Fulani herdsmen. They move from one locality to another and at the beginning of Round 2 enumeration, they were not present in some of the communities.

In Kintampo, 61,774 people were registered in 73 communities in Round 1 while 63,762 people were registered during Round 2 in 76 communities. Here, there is a difference in the number of communities which could explain the high number of people registered during the second round.

However, project success is not based on the number of communities included in the project, but on the development of a dynamic strategy called ‘implementation phase’ which included a sensitisation campaign, a training session and the registration phase and also the consideration of disability within the MDA system. Concerning MDA in the community the most important issue is compliance. According to Kyelem et al[1], it is valuable to develop “compliance profiles” of communities to identify those groups of individuals who remain “persistently non-compliant” during MDAs (for example children, upper socio-economic classes, young men, people of older ages and people with disabilities), and then determine the causes of this non-compliance and effective approaches to overcoming it[v]. During this project, the sensitisation campaign provided information concerning the project and its advantages. The training was successful in increasing knowledge, changing the perception of health workers and CDDs mostly concerning the identification and the

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[1] Kyelem D, Biswas G, Bockarie MJ, et al. Determinants of Success in National Programs to Eliminate Lymphatic Filariasis: A Perspective Identifying Essential Elements and Research Needs. *The American journal of tropical medicine and hygiene*. 2008;79(4):480-484.

consideration of disability. The introduction of the WGSS was important because it brought a new way to identify people with disabilities. This approach is consistent with evidence from earlier research in Africa, which showed that the main factors facilitating the implementation of MDA programmes were creating awareness through innovative community sensitisation programmes, the creation of partnerships and collaborations, integration with existing NTD programmes, motivation of CDDs through appropriate incentives and training mechanisms (7).

Prevalence of disability

The prevalence of disability identified varied considerably between villages as well as between rounds. In Tano South, 0.8% of those registered reported having a disability in Round 1, raising to 3.2% in Round 2. In Kintampo North, there was a similar difference between Rounds 1 and 2: the prevalence in Round 1 was 1.7% and in Round 2 was 3.4%. The higher disability prevalence in the second round can be explained by the increased understanding of the CDDs of how to administer the WGSS as well as the understanding and willingness of people with disabilities to answer the questions. This data is comparable to the 2010 population and housing census - during this census, the national prevalence on disability was 3% and that of Tano South district and Kintampo was 2% and 2.6% respectively (4).

The findings on the increased understanding of disability and the needs of people with disabilities by health workers and CDDs is encouraging. It has long been recognised that people with disabilities have not always benefitted from progress driven by the SGDs due to a lack of specific focus on their inclusion, which meant that the multitude of barriers people with disabilities face in their daily lives will have been too great to allow their full participation[vi]. In order to design the MDA more inclusively, this project introduced a number of activities within the MDA such as community health education and sensitisation, registration and health worker/CDD training. Health workers, CDDs and institutions such as churches, mosques, schools and health centres played an important role in driving health education. The project also used innovative, locally relevant and context-specific strategies of communication to provide community sensitisation to facilitate the implementation of MDA with assessment of disability.

One important finding of this project was the increased knowledge of health workers and CDDs on disability. The increased knowledge changed the perception of disability and people living with disabilities. Participants felt that they are now able to respond to the needs of persons with disabilities in the community. It has long been recognised that practical training is more effective than didactic classroom teaching alone[vii]. In this project, health workers and CDDs received training on how to assess disability using the WGSS. The questions are designed to identify people who may be at risk of non-participation due to limitations they face in performing basic activities. The focus on measuring functioning in core domains is in contrast to approaches that are based on impairments, deviations or loss in various bodily structures (3). The findings of this evaluation suggest that the contents of the training are understood and well received by both qualified health workers and CDDs.

Unplanned results

One indisputable area of success is that the pilot contributes an important dataset to a setting where little information on disability exists. There is very little known about the magnitude and types of disability found in rural Ghana and this data will be useful for the health services and others in both understanding the situation and planning inclusive services for the community. This was recognised by stakeholders interviewed who identified multiple practical uses for the dataset and who voiced ownership of the data that they helped generate. This highlights a hunger for information on issues such as disability affecting populations by health and social care workers. Opportunities for embedding questions such as the WGSS in other data collection activities should be sought and promoted to meet this demand.

However, the disability prevalence estimates made in the MDA campaigns need to be treated with caution for a number of reasons. First, although the data collected in the pilot was similar to the Ghana census estimates, the prevalence was lower than in many other settings, where the WGSS was applied[2][3][4]. One reason reported in the literature to explain this is that despite the training of data collectors on the importance of avoiding the word "disability", the word or its local equivalents are unintentionally used during the survey; the prevalence estimates are often lower in such settings. Another important factor is that although MDAs aim to target the entire population of the affected areas, some programmatic data suggest that CDDs do sometimes avoid remote, inaccessible or otherwise difficult to reach communities. Also, ivermectin MDAs exclude pregnant women and children under five, and often those who are not at home due to work, travel or another reason. It is therefore possible that populations included in MDAs are not fully representative of the entire population of the area and that the extrapolation of the collected disability data to the entire population may be inaccurate. It is also important to note that the audit conducted as part of this evaluation identified a number of issues with recording disability data by CDDs and the ranges of disability estimates between the villages were quite high, which is likely to be due to how CDDs understood and applied the WGSS in various settings. Further research on the completion and accuracy of disability data collected by CDDs is required.

This study highlighted many issues around MDA generally, which the pilot went some way to addressing. These include the importance of maintaining significant numbers of CDDs and supervisors to conduct MDA activities comfortably, recruiting CDDs from the local community to ensure understanding of language and cultural norms, retraining existing CDDs, and training them on softer skills such as being polite to community members. The pilot also highlighted how important community leader sensitisation and buy-in to activities such as these are in some communities. The activities mentioned above may have been well-planned when CDTI was

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[2] Madans, J.H., Loeb, M.E. and Altman, B.M., 2011, December. Measuring disability and monitoring the UN Convention on the Rights of Persons with Disabilities: the work of the Washington Group on Disability Statistics. In *BMC public health* (Vol. 11, No. 4, p. S4). BioMed Central.

[3] Loeb, M.E., Eide, A.H. and Mont, D., 2008. Approaching the measurement of disability prevalence: the case of Zambia. *ALTER-European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap*, *2*(1), pp.32-43.

[4] Mactaggart, I., Kuper, H., Murthy, G.V.S., Oye, J. and Polack, S., 2016. Measuring disability in population based surveys: the interrelationship between clinical impairments and reported functional limitations in Cameroon and India. *PloS one*, *11*(10), p.e0164470.

originally designed, but budget and time pressures meant that they were no longer prioritised when planning activities, to the detriment of community buy-in and the uptake of treatment. There were also issues with delayed MDA due to the rainy season, as were the low levels of education among some CDDs who struggled with reading and writing.

Pilot limitations

The pilot was subject to a number of limitations which need to be taken into account when interpreting and using its results. Firstly, the lack of ‘control’ districts with which to compare treatment numbers and refusals would have been important to understand the impact the intervention had on the overall uptake of services. A cost analysis component was also planned initially but could not be carried out, mainly due to limited internal capacity at the time of the project.

Secondly, we did not send specially trained data collectors to verify the disability data collected by CDDs. This is a major weakness of the evaluation, since if the CDDs asked the questions incorrectly or recorded the responses incorrectly, these errors would not be picked up by the audit.

Thirdly, many communities in the pilot areas were itinerant, meaning that comparing data between rounds was not easy as villages changed in size or disappeared and reappeared from year to year. Furthermore, although the WGSS was available in two local languages, several communities were speaking in other languages and translation of the questions was challenging for CDDs, many of whom also did not speak the local languages. A thorough mapping of local languages, along with professional translation and cognitive testing, could have alleviated these difficulties. It is also possible that the purpose of the data collection was not universally well explained to the participants, meaning that false expectations of service provision was raised in some cases. Although the project had identified the nearest services for people to be referred to, there were no funds to facilitate such referrals and travel costs would have prohibited most people from taking up those services.

Finally, the MDA process itself had multiple issues, described above, which are difficult to disentangle from the problems introduced or exacerbated by the introduction of disability data into the process.

Appendices

Appendix 1: Project proposal

1. NTD project identified for disaggregating data by disability

Please identify a project which would be suitable for disaggregating data by disability

Project name: **Ghana NTDs (Oncho/LF) Project**

Project number: **43023**

Start/end date of the project: **January 2012 to December 2015**

Donors: **Zochonis Charitable Trust**

Partners: **Ghana Health Service**

Project Officer: **David Agyemang**

2. Suitability of the project identified for disaggregating data by disability

Why do you think this project is suitable for disaggregating data by disability?

- Data collection in this project is easy and it would not be difficult to include data on disability
- This project is suitable for disaggregating data by disability because it collects data on a large number of people each year (about 11 million persons each year)
- This project also collects data from cities and urban areas, as well as very poor and rural areas, where stigmatisation and discrimination against persons with disability are expected to be relatively higher. This would enable us to better assess whether there is any difference in the way PWDs are treated in these two areas.
- Furthermore, both Oncho and LF leads to disability (blindness and elephantiasis which often lead to amputations) and therefore collecting data on disability in this project moves us a step further from being concerned about preventing these disabilities to being concerned about the quality of life and integration of these PWDs into society.

Please specify the geographical focus of your project

The Oncho/LF project is a nationwide project, but the pilot phase of the data disaggregation project will be carried out in two districts of the Brong Ahafo Region. These are the Kintampo North District and the Tano South District.

Brong Ahafo is the second-largest region in Ghana with a land area of 39,558 km² with 27 administrative districts/municipalities. It covers 16.6% of the country's total land area. The 2010 Population and Housing Census estimated Brong Ahafo region's population at 2,282,128 (GSS, 2010) with an estimated growth rate of 2.2% (against 2.4% national average).

Tano South District lies between latitudes 7º00’N and 7º25’ N and between longitudes 1º45 W and 2º15 W. The district has a total land area of 1,500km^2, which is 3.8 percent of the total land area of the Brong Ahafo Region. It is the entry point into Brong Ahafo Region from southern Ghana. Tano South District has an estimated population of approximately 61,693 with a growth rate of 1.8%. About 11,843 people are at-risk of onchocerciasis in the district.

Kintampo Municipal has an estimated population of 111,122 comprising 49.1% male and 50.9% female, with a growth rate of 2.6% (2000 Population Census). Because of the fertile nature of the land, migrant farmers from the north move to settle on arable lands where they can get enough farm produce, consequently the area has a potential of population explosion. About 73.1% of the municipal population live in the rural areas and 26.9% live in the only urban centre, Kintampo. About 73,537 people are at risk of onchocerciasis in the district.

Please describe the objectives of your pilot project regarding disability disaggregation

The objectives of this project include:

- To train NTD officers to collect and analyse data on disability
- To identify the proportion of MDA beneficiaries who have disabilities
- To identify the proportion of registered PWDs benefitting from MDA each year
- To identify the types of disabilities affecting persons who access MDAs
- To advocate for more accessibility for PWDs in the NTD programme and other related programmes based on data collected under this project
- To advocate for more disaggregation of data in the NTDs programme

Please indicate any indicators for measuring success

- Proportion of NTDs indicators disaggregated by disability
- Proportion of NTDs officers in target districts trained on disability data disaggregation
- Proportion of CDDs in target districts trained on disability data disaggregation
- Number of PWDs registered to participate in MDAs
- Proportion of registered PWDs benefitting from MDA each year

Please indicate what indicators/outputs will be disaggregated

- Number of primary health care workers (paid professionals) trained
- Community drug distributors (CDDs) trained
- Number of people treated for oncho (via MDA)
- Number of people **treated for LF (via MDA)**

Please provide us with a detailed timeline of activities, using a Gantt chart or similar tool, and assign responsibilities to each activity

See Appendix 2

Please describe your plans to evaluate the project, including the key questions, critical review of the data and qualitative investigation into the project implementation

There would be an end of project evaluation for this project. This evaluation would enable us to assess whether services are accessed by people with disabilities at the same proportion as people without disabilities, whether the services are accessible for people with disabilities or what barriers prevent people with disabilities from accessing the services. Some of the questions that would be asked are:

- What is the relevance and value added by disaggregating data by disability considering local and national development priorities and policies?
- How efficient was the implementation and what were the key successes or constraining factors regarding the disaggregation of data by disability?
- To what extent is there a likelihood of data disaggregation by disability continuing in the pilot region, and extending to other regions?
- What is the usefulness of disaggregated data by disability to the partner, Sightsavers, other partners and the government?

Please provide us with a detailed budget, including the cost of evaluation and the development of the HMIS system

See Appendix 3

Please describe what technical support you may require to effectively deliver and/or evaluate the proposed activities

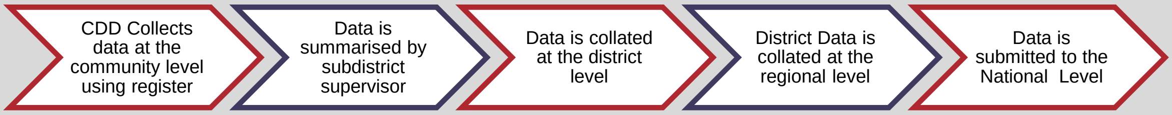
The required technical support will be in the area of assisting the CO to understand the tools to be used for data disaggregation, providing ongoing technical support during actual field data collection, and in evaluating the process. This is especially related to experiences gained in implementing this project in other countries.

3. Data collection method

Please explain how you currently collect data (methodology/tool) in this project and how you plan to collect disability disaggregated data using the Washington Group Short Set of questions.

The primary treatment data is currently being collected by the CDDs using a form designed by the national programme. This template only disaggregates data by gender. A second form, the summary sheet, is then used to summarise the data per community, basically the number of people treated, and the disaggregation by gender. Data collation/summarisation continue at each higher level.

The CDDs move from house to house in each community or village to collect the data. The chart below depicts how data flows from the community level to the national level.



The disaggregated data by disability will have to be written at the back of the form for collecting the primary data, and also summarised at the back of the summary sheet. Alternatively, the forms can be revised to include provision for data disaggregation by disability to be used only by the pilot districts/region.

Please indicate how the collection of disability disaggregated data will be used to uncover the challenges that persons with disabilities face

The national PHC has estimated the number of PWDs in Ghana. Normally, the data collected is used to assess the treatment coverage for the population at risk, but this study will also assess the treatment coverage among PWDs, the challenges they face in accessing the treatment, and actions taken to resolve identified challenges.

Furthermore, many of the districts where data is collected for this project are very rural ones where stigmatisation and discrimination against persons with disabilities are expected to be relatively higher. It is therefore important to collect data on disability so that we can be sure that PWDs are not in any way at a disadvantage regarding their ability to access the services in this project. This project would also enable us to identify the types of disabilities which the people who access our services have and thereby enable us to understand whether we are serving them well and how we can improve our services in order to serve them better.

Generally, however, this pilot will provide up-to-date information on PWDs and this information will be available to other stakeholders for the purpose of planning. It will also provide information on how to disaggregate data by disability.

4. Management of disability disaggregated data

Please explain how you currently consolidate/aggregate the data collected in this project and how you plan to manage disability disaggregated data

As described above, the primary data is collected by CDDs at the community level. The data is then summarised using the summary sheet, and submitted to the sub-district. The sub-district then collates the summarised data from the communities for the sub-district using the summary sheet. The sub-district summarised data is then sent to the district. The district collates data from the sub-district summary sheets for the district. The district summary sheet is sent to the region, the region does same collation and sends to national, and the national collates data from the regions to represent the country.

The disaggregated data by disability will travel along the same route as described above, especially if the primary data collection and summary forms are revised to include disability.

5. Disaggregation of data by disability at national level

Do you know if data on disability is available at national level? If yes, do you know what questions are included in the national census?

Information on persons with disabilities is collected during national population and housing censuses. Persons with disability were defined in the census as those who were unable to or were restricted in the performance of specific tasks/activities due to loss of function of some part of the body as a result of impairment or malformation. Information was collected on persons with visual/sight impairment, hearing impairment, mental retardation, emotional or behavioural disorders and other physical challenges. The respondents were asked whether they had disability (unable to or were restricted in the performance of specific tasks/activities due to loss of function of some part of the body as a result of impairment or malformation) and if yes, what disability they had.

6. Risk assessment

Please identify any risks related to the collection of disability-disaggregated data

- The CDDs will view this as extra work for them and might request for compensation.
- Making provision on the primary data collection and summary forms for the collection and collation of disaggregated data by disability will come at a cost since these will have to be redesigned and printed.
- The national programme might not see the need and use of data on disability.

Appendix 2: Project work plan

No	Activity	Responsibility/ Lead	2016												2017			
			Jan	Feb	March	April	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Q1	Q2	Q3	Q4
1	National level planning workshop	David		▨														
2	Finalisation of tools, training materials and guidelines	David		▨	▨													
3	District level training	David			▨													
4	Identify district level data entry persons	David			▨													
5	Training of CDDs	David			▨	▨												
6	Piloting of tools in one community	David			▨	▨												
7	Community sensitisations	David			▨	▨												
8	Data collection 1 (MDA)	All				▨	▨		X									
9	Post MDAs review meeting	All					▨											
10	Data validation and analysis	Eric						▨	▨									
11	Monitoring	David				▨	▨	▨	▨	▨	▨	▨	▨	▨				
12	Half year assessment	Eric							▨	▨		X						
13	Refresher training	David									▨	▨						
14	Data collection 2	David										▨	▨					
15	Post MDAs review meeting	David											▨					
16	Data validation and analysis	Eric												▨				
17	Final assessment	Eric												▨				

Key

Plan	▨
Actual	X

Appendix 3: Project Budget

ANNUAL BUDGET FOR THE NTDs DATA DISAGGREGATION PROJECT

Estimated number of health workers involved	**30**
Estimated Number of Volunteers involved	**276**
Number of districts involved	2

No	CATEGORY	Objective/Activities	Description	Unit Cost	Quantity required	# of Days	Freq.	Total Cost¢
	National level Buy-in and planning workshop	Travel and Transport (T&T)	T&T @ GHS 100/person/day x 8 officers	100.00	**8**	**2**	**1**	1,600
		Lunch, snack and water	Lunch, snack and water @ GHS 60.00 x 12 persons	60.00	12	2	1	1,440
2.0	Training of health workers and volunteers	T&T for Volunteers	GHS 15/CDD X 276 CCDs in the 2 districts	15.00	276	1	2	8,280
		T&T for health workers	GHS 50/officer X 12 officers/district x 2 districts	50.00	12	1	2	1,200
		Accommodation for National and regional officers	Accommodation @ GHS 200.00 x 5 persons	200.00	5	1	2	2,000
		Lunch (volunteers and health workers)	Lunch @ GHS20.00 x 300 persons	20.00	300	1	2	12,000
		Fuel	20gal/day @ GHS 16/gal x 2 vehicles x 2 days	16.00	20	2	2	1,280
3.0	Data Collection	Revision of Data collection Tools	GHS 5/register x 300 registers	16.50	500	1	1	8,250
		Lunch for volunteers	GHC 50/Volunteer x 276 volunteers x 2 treatments	50.00	276	1	2	27,600
		Transcription	Transcription cost @ GHS 100/transcriber/day x 10 days x 5 transcribers	100.00	5	10	2	10,000
4.0	**Post MDAs Review**	Accommodation for National participants	GHC 200/officer x 2 officers X 2 Night	200.00	2	2	2	1,600
		T&T for district participants	GHS 100/officer X 3 officers/district x 2 districts	100.00	6	1	2	1,200
		T&T for Volunteers	GHS 15/CDD X 276 CCDs in the 2 districts	15.00	276	1	2	8,280
		Lunch (volunteers and health workers)	Lunch @ GHS20.00 x 300 persons	20.00	300	1	2	12,000
5.0	**Monitoring**	Fuel for Monitoring staff	20gal/day @ GHS 15/gal x 5 days x 2 treatments	20.00	15	5	2	3,000
		Per Diem for Field staff	Per Diem @ GHS 100/Officer x 10 officers x 5 days	100.00	10	5	2	10,000
		Accommodation	GHC 100/officer x 5 officers	100.00	10	5	2	10,000
6.0	**Evaluation**	End of Project Evaluation		10,000.00	1	1	1	10,000
		GRAND TOTAL (in GHC)						129,730
		GRAND TOTAL (in GBP)						**24,024**

Appendix 4. Evaluation plan

Question	Data collection method	When	Who
1. How does the data collected from this project compare with existing data on disability available for the project and what may explain the differences?	Project data collected using the agreed designed/adapted tools. Census data is publicly available online and any other relevant sources.	At the end of the project	Project staff as agreed in the monitoring plan.
Policy, decision-makers and implementers			
Expectations			
A. What are the views of implementers and policy/decision-makers on the data currently available to them related to people with disabilities and their access to projects, and how do they think it can be improved?	In-depth interviews with policy/decision-makers and implementers involved in the project. This should include people who were involved in designing and managing the project as well as anyone who looks at or uses the project data that is produced. This work should include: • Mapping the key stakeholders and review throughout the project • Developing an interview guide that can be used to ensure the questions are covered in detail • Conducting the interviews with a tape recorder if possible • Transcribing/translating the interviews • Analysing the interviews for themes and patterns. Depending on the number of interviews, this could be done by hand or using a software package. • Following up with some stakeholders at key points throughout the project including after they have received a first set of data disaggregated by disability and at the end to see how their expectations and views change and how the data is meeting their needs.	At the beginning of the project only	This will require one or possibly two people (from the project's team or Country Office) to conduct the interviews, plus support with transcription/ translating. It is likely the interviewers would want to be involved in data analysis.
B. What are the expectations of implementers and policy/decision-makers of a data collection system that disaggregates project data by disability and how do they envisage it impacting on their decisions/work?			
C. How do implementers and policy/decision-makers understand issues around the accessibility of persons with disabilities to projects, and how do they see data as playing a role in accessibility?		At the beginning and at the end of the project	
Sensitisation and training			
D. How useful is the definition of disability provided by the Washington Group to implementers and policy/decision-makers and how does it complement their own understanding of disability?			
E. What are the views of implementers and project managers on the sensitisation/training provided to them, their staff and data collectors and how do they perceive it has affected the way they conduct their work?		During MDA review meeting and at the end of the project	
F. What are the views of implementers and project managers on the sensitisation provided to stakeholders identified in the stakeholder mapping?			
Process and tool			

Question	Data collection method	When	Who
G. How can the MDA process be best adapted to collect quality data on disability data without creating delay in drug delivery, and is registration the best time to collect disability data? (How does the appropriate data collection methodology impact on the quality and timeliness of the data available to implementers and policy/decision-makers?)			
H. How have different partners collaborated on this project and what impact can they attribute to partnership working?			
I. What are the cost and time implications of disaggregating data by disability for partners? Is the approach developed sustainable?	Comparison of two districts (one where disability data is collected and one where it is not) in terms of: (1) Time necessary to conduct MDA (2) Extra cost attached to collection of disability data. This will include looking at the extra time and cost attached to training, data collection and analysis, plus any extra resources needed for this project. Timesheet for staff and detailed budget will have to be developed	During MDA review meeting and at the end of the project	Project staff as agreed in the monitoring plan.
Data			
J. How does collecting data on disability impact on the main output of the project in terms of coverage and people reached?	Comparison of the same district: what is the coverage before the intervention (baseline) compared to the coverage after the intervention? We will be looking at the number of people treated.	At the end of the project	Project staff as agreed in the monitoring plan.
K. Is the data provided by the data collection system to implementers and policy/decision-makers to the correct level of detail?	As above, in-depth interviews with policy/decision-makers involved in the project. This should include people who were involved in designing and managing the project as well as anyone who looks at or uses the project data that is produced.	During MDA review meeting and at the end of the project	This will require one or possibly two people (from the project's team or Country Office) to conduct the
L. What data would implementers and policy/decision-makers like to have access to that remains unavailable?			
M. How has the data collected to date been used in any way by implementers and policy/decision-makers?			
Next Steps			

Question	Data collection method	When	Who
N. How have implementers and policy/decision-makers integrated any aspect of this project into other projects over which they have control, including disability awareness and collecting data on disability?			interviews, plus support with transcription/ translating. It is likely the interviewers would want to be involved in data analysis.
O. How can lessons learned from this project be captured to implement this work in other projects and to share with partners and other organisations?			
Staff collecting/analysing the data			
Training			
P. How do the staff collecting/analysing the data understand disability and how can the training best orient them to the definition provided by the Washington Group?	Staff who will be involved in collecting and analysing the disability disaggregated data will participate in focus group discussions. • These will be small groups of 5-8 peers who are likely to feel comfortable talking in front of each other • There will be an interview guide developed for the interviewer to guide the discussion to ensure the groups cover all important questions • They should be recorded, transcribed and translated • They will be analysed for themes and patterns. Depending on the number of groups this could be done by hand or using a software package • At least some of the groups should be repeated at the end of the project to investigate how expectations and understandings have changed and how the project can be improved	To be discussed at the start, during the MDA review meeting and at the of the project.	This will require one or possibly two people to conduct the interviews, plus support with transcription/ translating. It is likely the interviewers would want to be involved in data analysis.
Q. How does orientation on disability issues affect the way staff interact with project clients/patients with disabilities or impairments?		To be discussed during the MDA review meeting and at the of the project.	
R. How do staff collecting/analysing the data understand the purpose of data disaggregated by disability and how can the training best orient them to understand the importance of accurate data collection?			
S. How are staff analysing the data and how can training best orient them to summarise and analyse data in a way that is useful for them?			
T. How often do staff require refresher trainings or support to maintain high quality data collection?			
Tool and Process			

Question	Data collection method	When	Who
U. How can the tools and processes currently used by staff to collect client data be best adapted to include disability data?			
V. How do the tools and guidelines developed specifically for this project fulfil their purpose and how could they be improved? (How does the appropriate technology, including hardware and software, impact on how staff are able to collect and analyse data?)			
W. What extra burden does collecting the disability data place on the staff working with the data in terms of their time and taking them away from other duties?	• Staff administering the questions should share their experiences straight after the MDA during a post-MDA monitoring meeting. They should be encouraged to record and share their experiences of explaining to the clients and asking them questions, recording the data and the extra time it takes them to gather this data in addition to their other duties. • Staff involved in maintaining/analysing the data can maintain regular 'diaries' of their experiences with collecting the data. The diaries will be collected by project staff on a regular basis, collated and analysed for themes, possibly using a software package. • Auditing a sample of the data collected. By choosing one or two indicators presented to decision makers, the numbers can be traced back through the data management system to original records. Discrepancies at each stage should be noted and remedial actions should be sought.	During the MDA review meeting	Project staff to organise post-MDA monitoring meeting to collect the data Country Office to carry out spot-check
X. How accurately can the data be transferred through the information system from the point it is collected from the client, to the final version received by policy/decision-makers?		Throughout the project	
Community			
Y. (For data collectors based outside of health facilities) How do staff feel that community knowledge/attitudes/norms affect the collection of this data and do they experience more challenges in specific groups within communities?	Staff who will be involved in collecting and analysing the disability disaggregated data will participate in focus group discussions. • These will be small groups of 5-8 peers who are likely to feel comfortable talking in front of each other • There will be an interview guide developed for the interviewer to guide the discussion to ensure the groups cover all important questions • They should be recorded, transcribed and translated • They will be analysed for themes and patterns. Depending on the number of groups this could be done by hand or using a software package • At least some of the groups should be repeated at the end of the project	During the MDA review meeting	This will require one or possibly two people to conduct the interviews, plus support with transcription/ translating. It is likely the interviewers
Z. What are the experiences of staff in administering the extra questions to project clients, including the reaction of clients to being asked these questions and using the tools provided for the purpose?			
Next steps			

Question	Data collection method	When	Who
AA. How have staff working on this project integrated any aspect of this project in to other work over which they have control, including disability awareness and collecting data on disability	to investigate how expectations and understandings have changed and how the project can be improved	To be discussed at the start, during the MDA review meeting and at the of the project.	would want to be involved in data analysis.
Project Clients providing data			
BB. How do project clients comprehend the questions as they are asked to them?	A very brief survey of a sample of clients in the community during post MDA monitoring. • The surveys should be developed to be very brief and easy to understand. It can include quantitative close-ended questions and some open-ended questions if required • Not every household has to be asked – every second or third client leaving over one day could be asked • The individual should be asked if they mind sparing five minutes to answer questions about their visit today • The surveys could be recorded on paper or straight onto a laptop database if it is possible to take that to the location • The data can be analysed using appropriate software	During the MDA review meeting and at the end of the project	One person to collect the data. Depending on how it is collected, they may require support to input the data to a computer and analyse the data
CC. How do project clients feel about being asked these questions?			
CC. How do project clients understand the reasons for the data being collected?			

Appendix 5: Blank Community Tally Sheet Excerpt (from CDD Register)

DISABILITY DISAGGREGATION DATA
DATE

COMMUNITY TALLY SHEET

Household	Number of persons in household	Age	Sex	Do you have difficulty seeing, even if wearing glasses?				Do you have difficulty hearing, even if using a hearing aid?				Do you have difficulty walking or climbing steps?				Do you have difficulty remembering or concentrating?				Do you have difficulty (with self-care such as) washing all over or dressing?				Using your usual language, do you have difficulty communicating				**With Disabilities (WD)**
				N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	
				N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	
				N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	
				N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	
				N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	
				N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	
				N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	N	YS	**YL**	**CN**	
	N = NO				YES, SOME DIFFICULTY						YL	=	YES, A LOT OF DIFFICULTY								CN	=	CANNOT		WD= Disabilities			

Appendix 6: Stakeholder mapping

Stakeholder name	**Type**	**Stakeholders' interests in the DD project?**	**Importance of this stakeholder for the success of the project?**	**Role of the stakeholder**	**How do we need to involve this stakeholder in the DD project?**	**How are we going to engage this stakeholder?**	**When are we going to engage with them?** *Link this to activities in the implementation plan and timeline (for example MDA March 2016)*
Ghana Health Services/NTD Programmes	Primary	They will use data for planning and implementation. Measure accessibility of PWDs to MDAs.	High	Planners, implementers	All	The GHS will act as the main implementers in the project; they are going to be engaged in the planning, implementing, training, reporting, monitoring and evaluation	Throughout the project
Food and Drugs Authority (FDA Laboratories, Near TUC HQ)	Secondary	Relationship between serious adverse effects and disability. Proper administration of drugs.	Low	Decision makers	Information (interest only)	When decisions are being made about severe adverse reactions	During cases of severe adverse reactions
Kumasi Centre for Collaborative Research (KCCR)	Secondary	Areas of research interest	Low	Collaborators	Reporting	Would be included in NTDs quarterly and annual report dissemination	During quarterly ICCC meetings and annual review meetings
Onchocerciasis Chemotherapy Research Centre (OCRC	Secondary	Relationship between serious adverse effects and disability. Proper administration of drugs	Low	Collaborators	Reporting	Would be included in NTDs quarterly and annual report dissemination	During quarterly ICCC meetings and annual review meetings
LF Support Centre, Accra	Secondary	Areas of research interest (in LF mobidity management)	Low	Collaborators	Reporting	Would be included in NTDs quarterly and annual report dissemination	During quarterly ICCC meetings and annual review meetings
GES/SHEP	Secondary	Involvement of school age children	Medium	Collaborators	Reporting	Would be included in NTDs quarterly and annual report dissemination.	During quarterly ICCC meetings and annual review meetings
West Africa Morbidity Project	Secondary	LF related disability	Medium	Decision makers	Reporting	Would be included in NTDs quarterly and annual report dissemination.	During quarterly ICCC meetings and annual review meetings

Stakeholder name	**Type**	**Stakeholders' interests in the DD project?**	**Importance of this stakeholder for the success of the project?**	**Role of the stakeholder**	**How do we need to involve this stakeholder in the DD project?**	**How are we going to engage this stakeholder?**	**When are we going to engage with them?** *Link this to activities in the implementation plan and timeline (for example MDA March 2016)*
World Health Organisation	Secondary	Therapeutic and Geographic coverages	Low	Collaborators	Reporting	Would be included in NTDs quarterly and annual report dissemination.	During quarterly ICCC meetings and annual review meetings
National Malaria Control Programme	Secondary	Co-implementation for Malaria and NTDs activities	Low	Collaborators	Reporting	Would be included in NTDs quarterly and annual report dissemination.	During quarterly ICCC meetings and annual review meetings
FHI360/ USAID	Secondary	Impact on MDA activities.	High	Collaborators	Active participation	Would be engaged in all meetings, trainings, implementation and reporting.	Throughout the project
Sightsavers	Primary	Feasibility of collecting DDD during MDAs. Use data for planning and implementation. Measure accessibility of PWDs to MDAs.	High	Planners, implementers	All	Main partners in support; technical, financial, meetings, training, monitoring, evaluation…	Throughout the project
Coalition of NGOs in Health	Secondary	Scalability of the project	Medium	Collaborators	Information (interest only)	Would be included in NTDs quarterly and annual report dissemination	During quarterly ICCC meetings and annual review meetings
Volta River Authority	Secondary	Collaborators with NTDs Programme	Low	Collaborators	Reporting	Would be included in NTDs quarterly and annual report dissemination	During quarterly ICCC meetings and annual review meetings
Partnership for Child Development (PCD)	Secondary	Collaborators with NTDs Programme	Low	Collaborators	Reporting	Would be included in NTDs quarterly and annual report dissemination	During quarterly ICCC meetings and annual review meetings
Catholic Relief Services	Secondary	Collaborators with NTDs Programme	Low	Collaborators	Reporting	Would be included in NTDs quarterly and annual report dissemination	During quarterly ICCC meetings and annual review meetings

Stakeholder name	**Type**	**Stakeholders' interests in the DD project?**	**Importance of this stakeholder for the success of the project?**	**Role of the stakeholder**	**How do we need to involve this stakeholder in the DD project?**	**How are we going to engage this stakeholder?**	**When are we going to engage with them?** *Link this to activities in the implementation plan and timeline (for example MDA March 2016)*
Water Research Institute (CSRI)	Secondary	Collaborators with NTDs Programme	Low	Collaborators	Reporting	Would be included in NTDs quarterly and annual report dissemination	During quarterly ICCC meetings and annual review meetings
Dodowa Health Research Centre	Secondary	Area of research interest. Scalability of the proje	Low	Collaborators	Reporting	Would be included in NTDs quarterly and annual report dissemination	During quarterly ICCC meetings and annual review meetings
Tullow Oil Company	Secondary	Collaborators with NTDs Programme	Low	Collaborators	Information (interest only)	No direct engagement under this project. May be approached by the NTDs programme for possible funding.	Not specific; as and when the need arises
UniBank Ghana Ltd.	Secondary	Collaborators with NTDs Programme	Low	Collaborators	Information (interest only)	No direct engagement under this project. May be approached by the NTDs programme for possible funding.	Not specific; as and when the need arises
Noguchi Memorial Institute for Medical Research	Secondary	Areas of research interest.	Low	Collaborators	Reporting	Would be included in NTDs quarterly and annual report dissemination	During quarterly ICCC meetings and annual review meetings
WACIPAC	Secondary	Collaborators with NTDs Programme	Low	Collaborators	Information (interest only)	No direct engagement under this project. Would be included in NTDs annual report dissemination	During annual review meetings
World Vision Ghana	Secondary	Collaborators with NTDs Programme	Low	Collaborators	Information (interest only)	No direct engagement under this project. May be approached by the NTDs programme for possible funding.	Not specific; as and when the need arises
Media group	Secondary	Collaborators with NTDs Programme	Medium	Collaborators	Information (interest only)	Would be included in NTDs annual report dissemination	During annual review meetings and Launching of MDAs
REGIONAL LEVEL							

Stakeholder name	**Type**	**Stakeholders' interests in the DD project?**	**Importance of this stakeholder for the success of the project?**	**Role of the stakeholder**	**How do we need to involve this stakeholder in the DD project?**	**How are we going to engage this stakeholder?**	**When are we going to engage with them?** *Link this to activities in the implementation plan and timeline (for example MDA March 2016)*
Regional Ministry of Health/NTD	Primary	They will use data for planning and implementation. Measure accessibility of PWDs to MDAs.	High	Planners, implementers	All	Technical support, meetings, training, reporting	Throughout the project
DISTRICT LEVEL							
District Health Administration	Primary	They will use data for planning and implementation. Measure accessibility of PWDs to MDAs.	High	Planners, implementers	All	Technical support, meetings, training and reporting, monitoring	Throughout the project
District Education Service	Secondary	Involvement of school age children	Medium	Planners, implementers	Communication (needs to be informed)	Would be informed about the MDAs, social mobilisation & sensitisation in schools. Attend district annual review meetings	During MDAs
District Social Welfare Department	Secondary	Collaborators with NTDs Programme	Low	Collaborators	Information (interest only)	Attend district annual review meetings	During annual review meetings
District Assembly	Secondary	Improved health in communities	Medium	Planners, implementers	Communication (needs to be informed)	Social mobilisation & sensitisation. Attend district annual review meetings	During MDAs
Assembly members	Secondary	Improved health in communities	Medium	Decision makers	Communication (needs to be informed)	Social mobilisation & sensitisation	During MDAs
Christian Council Organisation	Secondary	Collaborators with NTDs Programme	Medium	Collaborators	Information (interest only)	Social mobilisation & sensitisation	During MDAs
DPO members	Primary	Inclusion of PWDs	High	Target group	Communication (needs to be informed)	Beneficiaries, social mobilisation & sensitisation	During MDAs

Stakeholder name	**Type**	**Stakeholders' interests in the DD project?**	**Importance of this stakeholder for the success of the project?**	**Role of the stakeholder**	**How do we need to involve this stakeholder in the DD project?**	**How are we going to engage this stakeholder?**	**When are we going to engage with them?** *Link this to activities in the implementation plan and timeline (for example MDA March 2016)*
CHAG	Secondary	Collaborators with NTDs Programme	Medium	Collaborators	Information (interest only)	Training, social mobilisation, meetings	During MDAs
Traditional council	Secondary	Improved health in communities	High	Decision makers	Communication (needs to be informed)	Social mobilisation & sensitisation	During MDAs
COMMUNITY LEVEL							
Assembly members	Secondary	Improved health in communities	High	Planners, implementers	Active participation	Social mobilisation & sensitisation	During MDAs
Heads of churches	Secondary	Collaborators with NTDs Programme	High	Collaborators	Communication (needs to be informed)	Social mobilisation & sensitisation	During MDAs
Community health workers [CHEW]	Primary	Improved MDAs indicators.	High	Planners, implementers	Active participation	Training, monitoring, social mobilisation and sensitisation, meetings	During MDAs
Local DPO Groups	Primary	Inclusion of PWDs	High	Target group	Active participation	Beneficiaries, meetings, social mobilisation and sensitisation	During MDAs
Community Volunteers	Secondary	Improved health of community members	High	Planners, implementers	Active participation	Training, monitoring, social mobilisation and sensitisation, delivery of drugs	During MDAs
Community Information officers	Secondary	Awareness creation	High	Collaborators	Information (interest only)	Social mobilisation & sensitisation	During MDAs
Traditional leaders ie Chiefs and the elders	Secondary	Improved health of community members	High	Decision makers	Active participation	Social mobilisation & sensitisation	During MDAs

Stakeholder name	**Type**	**Stakeholders' interests in the DD project?**	**Importance of this stakeholder for the success of the project?**	**Role of the stakeholder**	**How do we need to involve this stakeholder in the DD project?**	**How are we going to engage this stakeholder?**	**When are we going to engage with them?** *Link this to activities in the implementation plan and timeline (for example MDA March 2016)*
Town/community council	Secondary	Improved health of community members	High	Decision makers	Active participation	Social mobilisation & sensitisation	During MDAs
Local Parents Support Groups	Primary	Improved health of community members	High	Target group	Active participation	Social mobilisation & sensitisation	During MDAs
HeadMasters	Secondary	Involvement of school children	High	Planners, implementers	Communication (needs to be informed)	Social mobilisation & sensitisation	During MDAs
Local food Vendors association	Secondary	Collaborators with NTDs Programme	Medium	Collaborators	Communication (needs to be informed)	Social mobilisation & sensitisation	During MDAs

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