Sightsavers

Disability Disaggregation of Data - Baseline report

Emma Jolley, Pauline Thivillier and Fred Smith
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Acronyms

CDD	Community Drug Distributor
CO	Country Office
DFID	Department for International Development
DHS	Demographic and Health Survey
FGD	Focus Group Discussion
HLP	High Level Panel
HMIS	Health Management Information System
IANET	Integrated Approach to NTD Elimination in Tanzania
IDC	International Development Committee
IEC	Information, Education and Communication
M&E	Monitoring and Evaluation
MDA	Mass Drug Administration
MDGs	Millennium Development Goals
MPUSP	Madhya Pradesh Urban Eye Slum Project
NGO	Non-Governmental Organisation
NTD	Neglected Tropical Disease
OA	Ophthalmic Assistant
PEC	Primary Eye Care
PDA	Programme Development Advisor
PWDs	People with Disabilities
TT	Trachoma Trichiasis
UN	United Nations
WG	Washington Group

Acronyms

Executive summary

Summary:

This baseline report contains information on the initial steps (prior to the start of data collection) undertaken to include disaggregation of data by disability in two projects in Tanzania and India. The report includes information on project selection, development of an Monitoring and Evaluation (M&E) plan, adaptation of data collection tools and training of Country Offices (COs) staff, partners and data collectors. This baseline also captures the knowledge, attitudes and practices of programme managers, decision makers and data collectors around disability, the availability of data, and the experiences of Sightsavers' implementing staff. The main objective of this report is to provide a record of the situation in the two sites at the start of the pilot projects against which progress can be compared. Additionally it will report qualitative information that will inform future disaggregation of data in Sightsavers' projects and enable us to share externally how we have gone about this project.

Methodology:

The information in this report is qualitative in nature and was captured through face to face interviews of project managers and decision makers (four in India and four in Tanzania), and focus group discussions (FGD) among data collectors (two in India and one in Tanzania) who participated in the training and field testing of the data collection tool. This report also captures a number of observations of Sightsavers staff implementing the project to reflect on some of the challenges that have arisen since the start of the project.

Overview of findings:

Accessibility of projects cannot be assessed without data on disability and current data is limited and insufficient to guarantee that our programmes are accessible. Barriers to access faced by people with disabilities were identified by programmes managers and decision makers at community, health facilities and government levels.

The Washington Group (WG) short set of questions was described as a useful tool to collect this data as it emphasises difficulties in performing basic activities and therefore reflects well accessibility issues. Nevertheless, the WG definition of disability which refers to functional limitations may lead to an elevated estimation of the number of people with disabilities compared to groups, including governments, who use a more medical definition of disability. Using functional limitation could also lead to over or under reporting of health-related limitations. To mitigate these concerns, sensitisation and advocacy activities on the WG definition and questions are essential.

It was recommended to include questions on disability in the demographic section of the Health Management Information Systems (HMIS) and data collection tools. The data collected will be used for programme planning and monitoring. Therefore, good quality data, documentation and learning are essential in order to inform project management and advocacy activities. It is also essential to use the data collected to make the process meaningful.

The social model of disability, including the fact that data collectors only record the answer and do not assert their own judgement on the patient is a concept that needs to be explained in details during training. It is also recommended to carry out training of data collectors in the local language in order to

ensure good understanding. Similarly, the translation of the questionnaire in local and plain language and the addition of standardised examples need to be reflected upon. Finally, concerns regarding the additional workload that will create the questionnaire are removed after some field testing and over time as people get use to the questionnaire.

Background

Data Disaggregated by Disability project

It is widely estimated that persons with disabilities did not benefit from the Millennium Development Goals (MDGs). It is felt that a major issue has been a lack of data providing evidence of where people with disabilities are and/or whether they were being reached. Partly as a result of Sightsavers and other groups lobbying, the UN High-Level Panel (HLP) report on the post-2015 framework recognised the need to measure programmes for specific marginalised group including people with disabilities and stated that targets 'will only be considered achieved if they are met for all relevant income and social groups'. The report strongly calls for all goals to measure progress by specific target groups, including people with disabilities, and that targets should not be considered as met unless they have delivered progress for all groups, including people with disabilities.

A recent UK Parliamentary inquiry into disability and development called on DFID to report disability disaggregated data from its programmes and to disaggregate targets in its Results Framework. In their response DFID committed to improving data on disability and to the principles of the HLP report that they had helped push for. DFID have stated they will now introduce a disability framework, central to which will be the ability to report data disaggregated by disability. There is therefore currently a context internationally around the post-2015 framework and within the UK that this project can make a significant contribution to, as DFID and other bilateral and multilateral donors are seeking evidence on what works.

As an organisation, Sightsavers is calling on other NGOs and donors to start disaggregating data by disability. However, currently we are collecting only disaggregated data by age and sex and are unable to provide concrete evidence and examples on how data can be disaggregated by disability. Thus, this project will allow us to:

- Expand how we disaggregate data in order to include people with disabilities.
- Share our experience of disaggregation with others.
- Advocate for the need to collect data specifically around people with disabilities.

This is a unique opportunity for Sightsavers to take part in an initiative which goes beyond the standard data collection practices of most other organisations. This initiative will ultimately serve to make our services more inclusive of people with disabilities and highlight the quality of the services we provide on the ground. It will demonstrate the effectiveness of our projects and programmes for people with disabilities and allow us to make change accordingly, driving up standards and improving quality.

Pilot projects

The first step in this project is to conduct small scale pilot projects with an aim to gather learning, especially on the process and experiences of disability disaggregation, before expanding the disaggregation to a larger scale. A call for proposals was made to pre-selected COs and two were

selected drawing on criteria that included geographical and thematic variety plus opportunities for innovation including use of new technologies.

The projects selected were the Madhya Pradesh Urban Slum Eye Care Programme (MPUSP) in Bhopal, India and the Neglected Tropical Diseases (NTD) Programme in Ruvuma, Tanzania. These projects are described thoroughly in Appendices 1 and 2, and briefly summarised here:

Madhya Pradesh Urban Slum Eye Care Programme in Bhopal, India

The project is piloting the establishment of a system of Primary Eye Care (PEC) through community resource building and strengthening human resources required in the slums of Bhopal and Indore. The project started in late 2013 and total project duration will be four and half years. Project partners include the development agency, AARAMBH, and the eye hospital, Sewa Sedan. The project will incorporate PEC in urban slum situation to address problems associated with massive population growth in these areas. The project's main objectives are:

- To build PEC services for selected slums and poor urban communities by the end of 2015.
- To increase demand for refractive error and other eye care services by increasing awareness within the target population and building links with different stakeholders, by the end of 2016.
- To develop human resources in terms of optical staff and community volunteers to provide services in the community.
- To carry out advocacy with the district administration to build referral mechanisms for other eye care services.

Disaggregation of data by disability will be incorporated in to all tools at points where patients/clients demographic data is collected. The development of an electronic HMIS specifically for this project provides an important opportunity for piloting the data disaggregation in an electronic format.

> **_Ruvuma Integrated NTD programme in Tanzania_**
>
> Integrated Approach to NTD Elimination in Tanzania (IANET) is implemented in Tanzania mainland and Zanzibar, both under the Ministry of Health. The main goal is to reduce morbidity due to NTDs in Tanzania through improved health and socio-economic well-being to a level that is no longer a public health problem by 2017. Programme Implementation level is at hamlet level, where by morbidity control interventions (surgeries) and Mass Drug Administration (MDA) at community and school are among the interventions.
>
> Disaggregation of data by disability will be incorporated in data collection tool in two areas:
> * Trachoma trichiasis (TT) camps – health care providers using paper forms
> * MDA – community drug distributors (CDDs) using registry book and mobile phone technology.
>
> Paper based data collection tools as well as mobile phone technology will be used to collect the disability disaggregated data. Using different formats and tools provides a good learning opportunity to understand how disability disaggregation of data works with different format/tools.

The overall question to be answered by the pilot projects is how can data disaggregated by disability be accurately collected on a project level in a resource-efficient way that is useful to policy and decision makers?

Methods

Questions and tools

Prior to the start of the pilots, a number of questions were identified as important by the project team for evaluating the pilot projects' success and capturing the experiences of people coming in to contact with the data system at a wide range of levels. Following initial interviews with key project stakeholders at the beginning of each project, further questions were identified and integrated in to the Evaluation Plan, the final version of which is detailed in Appendix 3. The methods used to answer these questions and the frequency with which they will be examined are also described in Appendix 3.

Although the majority of the questions posed in the plan require reflection on experience with the new system, a number of questions reflect on the views and expectations of both programme managers and staff working within the systems and how they change over the course of the project. It was therefore relevant to investigate and capture in this report those views prior to the commencement of any data collection, so as to be able to understand the changes.

The questions identified as relevant for answering by project managers and decision makers at the very beginning of the project were:

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

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

C. What are the views of 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?

D. What are the expectations of 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?

The question identified as relevant for answering by the staff involved in data collection at the very beginning of the project was:

Q. How can the tools and processes currently used by staff to collect client data be best adapted to include disability data?

In addition to answering the questions identified in the Evaluation Plan, this report also captures a number of observations and experiences of Sightsavers staff implementing the project to reflect on some of the challenges that have arisen since the start of the project.

Sightsavers

Results

Experiences of project managers and decision makers

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

Central Findings:

- The accessibility of projects cannot be assessed without data;
- There exist different and broad data needs among policy and decision makers;
- Barriers to access exist at community, health facilities and government levels.

Accessibility of projects cannot be assessed without data

Decision makers explained that in most cases they do not have the data to say how well people access their projects. Anecdotes tell them that some people with disabilities are accessing services but they have no idea of the proportion. Projects that specifically target people with certain disabilities are accessible but may not reach the entire population, for example projects or services targeting people with visual impairments.

"Eye health programmes – have dealt with partial or avoidable blindness for years through centres and outreach camps. However, programmes cannot be sure about other types of disabilities because the kind of information and data needed to know how much of services reach them is not currently collected."

"Only our Social Inclusion and Education projects target PWDs: we are not active in our eye health or NTD projects in targeting PWDs so we don't know yet whether the limitations are within our programmes or mainly within the community."

Different and broad data needs

Decision makers' thoughts on data needs varied widely. Some said that they would use the data to understand who was accessing their services and who was not and why. The availability of the data will allow them to tailor their programme to ensure that they are inclusive. Others identified more discrete and less germane roles for data focusing on certain disabilities, including developing groups of blind people for economic support activities.

"Making our programmes accessible means that we need to collect information on people with problems accessing services, including prevalence by the area. If we have interventions in a certain region we need to know the prevalence and types. "

> *"Disaggregating the TT surgery data by disability will help me identify how many blind people I have in my area and then I can organise them and improve my services to them, or organise them in to self-help groups for self-development including economically. There are also other disabilities associated with NTDs … if I know the data then we can direct our help to those people and those areas which are mostly affected."*

Barriers to access are at community, health facilities and government levels

The main barriers identified by the decision makers were at family or community level and centred on the lack of awareness that people with disabilities can go to mainstream services, or that in resource scarce situations, health care for people with disabilities is often deprioritised. Stigma around people with disabilities was also identified as contributing to the lack of access.

> *"Awareness is a barrier to attending services - families or carers may not know that PWDs can be taken to these places. Many PWDs are home-bound and may not be very independent unless they are accessing some sort of outreach group. Because they may not be engaged in many activities families may not see a need to get services for them. Inclusion in the real sense does not exist. As NGOs engage with PWDs and engage them in meaningful activities and work towards their inclusion, we find that then they come out of the hospitals and try to take the services that are available."*
>
> *"It's not always easy to move these people [with disabilities], so when they get sick the family might take a long time to take that person because they think if the difficulties of transporting and the expense. So these ones only come to the hospital when they are really very sick. Especially with mental disabilities – the communities are not knowledgeable of their behaviour so it can be hard for them to know when people are sick enough to go to hospital or not."*

Barriers at health service level are also an obstacle to inclusion, including inaccessibility of services for people with disabilities (especially people with physical impairments) or lack of sensitisation/awareness of the staff working in the facilities. The lack of support from the government was also identified as an issue. Accessibility is not ensured in many government services, including healthcare. Partners feel that ensuring the inclusion of people with disabilities is not a high priority for the government at the moment and this project could contribute to highlight this issue.

> *"Services are currently not reaching PWDs. Some government social services exist, but it is not enough... AARAMBH aims to be inclusive … all programmes include some provision for PWDs, but the government is not supportive enough."*
>
> *"The problems are on both sides. The services are not reaching them and they are not going there. And they don't feel that it's their right to go and access the services. Also the services are not made to be accessible to PWDs – people with wheel chairs and there's no ramp in the hospital then the person will not be able to go."*

"In the community as well as care provision areas, we don't have care provision for PWDs - there is no priority given to PWDs. We have priority given to under-fives and pregnant women but not PWDs – only older people. They don't get fee exemptions; they don't get priority in the line to see the doctor. In some hospitals they don't have accessibility to get in to that hospital."

"The sensitivity of service providers may be a barrier. They may not be able to communicate with people who have sensory disabilities and no support except from the family/ carer. Health centres may not be accessible, especially to those with physical impairments."

"The government has a lot of services – new schemes and facilities - but there is no awareness among the government itself that we need to provide information about the different schemes to the PWDs- - schemes for pregnant women for example need to be marketed to PWDs and made accessible to them."

"PWDs may not have the capacity to reach out to services themselves or to advocate for access. Exclusion from health services is typical of other sectors – education, employment, etc. Specific advocacy activities from interest groups can help, but they do not happen very frequently."

B. How useful is the definition of disability provided by the Washington Group (WG) to policy/ decision makers and how does it complement their own understanding of disability?

Central Findings:

- The WG's emphasis on difficulties in performing basic activities is useful to reflect accessibility issues;
- The WG definition may lead to an elevated estimation of the number of people with disabilities compared to groups, including governments, who use a more medical definition of disability;
- Sensitisation and advocacy activities on the WG definition and questions are necessary to ensure better understanding of disability;
- The WG definition is not perfect and could lead to over or under reporting of health-related limitations.

The WG definition's emphasis on difficulties in performing basic activities is useful to reflect accessibility issues

There was a general agreement that the definition articulates the issue that may actually be preventing people from accessing services. The emphasis on difficulties experienced when performing basic activities is a good reflection on the issue of accessibility and avoids issues of stigma that may affect either the data collector or the client. Moreover, as it does not refer/require any medical knowledge, it ensures that data collectors without medical background, such as community volunteers, can collect the data.

"The WG definition is useful because it is about activities and participation and talks about the level of participation/ difficulties experienced by the people... The focus on activities and a range of difficulties are a useful combination. This means that not only disabilities that are visible but also a lot of non-visible disabilities - this will be able to assess people with limitations in different functional areas."

"It is clear in this case; it is about limitations that people experience. For me this addresses the issues around stigma that we have had. I think talking about limitations makes it easier for individuals to respond, as it avoids giving potentially stigmatising labels. For me the message is clear."

"The WG definition is quite good because it can be used by anyone, especially in the community to identify PWDs that they cannot do this and that. Instead of identifying them by their problem or their diagnosis, so CDDs [Community Drug Distributors] can do that, sub-village leaders, etc."

The WG definition may lead to an elevated estimation of the number of people with disabilities which may not be well received by government using a more medical definition of disability

In India, where there is a legal definition of disability as well as another definition used in the census, there is concern that a more functional definition of disability, which is likely to lead to an elevated estimation of the population who have a disability, may not be well received by government representatives. In that respect, sensitisation of the data collector and advocacy activities with the government on the WG definition and questions are essential.

"This is a functional definition and it clearly indicates that the person who is disabled is just like us, but because of certain conditions, he is not able to perform certain activities... Sensitisation is again important... in our country there is more stress on the medical definition, it's a fact. Some people try to make the benefits by using the certificate and applying."

"Once we have hard figures it will be hard for the government to accept them especially as efforts were made during the census to train the enumerators on the issue of disability, it will be difficult for them to accept, but once it is explained that was functional aspect of the disability rather than disability per se, it could be related to many other reasons other than disability, so I think it's going to be taken well, but of course we might have to do some special advocacy for this to sensitise them to the functional aspect of disability which includes issues like age that is not accounted for in the medical definition."

Sensitisation and advocacy activities on the WG definition and questions are necessary to ensure better understanding of disability

Policy / decision makers all recognised that the WG definition and questions are a useful tool for sensitising staff on issues of disability and appreciating that not all disabilities can be seen. It was also

highlighted that the questions would likely pick up people affected by issues such as old age and malnutrition.

> *"It's okay to use the functional [WG] definition so we can properly sensitise our staff so they can be more sensitive and not see PWDs in a sarcastic way and they don't have to use any bad words ... The functional definition will help them think that they have to use proper terminology before asking any questions to them. The functional definition is a starting place - it gives a clear idea about the project. E.g. age is not a disabling factor. But old people have a lot of functional impairments which limits them from attending services."*
>
> *"WG definition is useful as this complements the idea of knowing how people are disabled and how people face barriers to our programmes... it also covers certain aspects as related to malnutrition or general weakness, or you know, general sickness, age, etc, this throws light on other aspects that may create barriers - -general health conditions, sanitation conditions, faced by these people."*

The WG definition is not perfect and could lead to over or under reporting of health-related limitations.

Concerns were raised regarding the potential for over and under reporting of limitations experienced by people that are related to permanent health conditions. Conflation of health-related permanent disability with participation restrictions associated with aging, or temporary restrictions associated with illness or pregnancy could inflate the number of people recorded as being functionally disabled. Similarly, the lack of focused questions relevant to mental health problems could result in many people with permanent disabilities being excluded from the numbers recorded.

> *"The functional WG definition may need changing a bit to reflect other limitations that are not related to a particular impairment that could be wrongly captured; for example it would be good to exclude age related limitations. If it could say something about mental or health conditions that would be best."*

C.   What are the views of 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?

> *Central Findings:*
>
> - Current data on disability available is limited and insufficient;
> - Data on disability should be included in HMIS and data collection tools.

Current data on disability available is limited and insufficient

Generally there is very little data available on disability, and what does exist tends to be very general or at insufficient detail for project planning. For example, many programme managers rely on the global

estimates described in the WHO World Disability Report that described 15% of the global population having some form of disability. The only sources available are the national census, surveys or reports by other NGOs which may focus on a selective population or at a too general geographic area.

> *"Currently use [Indian] 2011 census data on PWDs which includes a very medical question. It may not capture the whole picture but it is a starting place. There have been a few surveys taken place, mostly initiated by NGOs or occasionally the government, but generally there is little data available and one has to extrapolate WHO or national data down to the local context. Therefore relevance is limited to MP [Madhya Pradesh]/ Bhopal."*
>
> *"There are no specific places to get data at the moment, except for official reports, for example from the [Tanzanian] census. The report on household surveys, e.g. the DHS - they don't focus much on disability but these are the documents we currently use and they give a general prevalence of disability."*
>
> *"When designing the NTD projects we referred to general population data - -didn't include any disaggregation data - just NTD prevalence and population numbers.*
>
> *"For social inclusion and education we use data from Tanzania League of the Blind to project planning. This is the number of people registered blind with TLB. They can also use census data down to regional level and compare with the TLB registration data. Don't use any disability data in the eye health and NTD programmes."*

Data on disability should be included in HMIS and data collection tools

Generally they all agree that the HMIS and data collection system should include questions on disability so they can improve programme design and planning.

> *"Need an inclusive data system where any organisation or person looking for data on people accessible projects can see a breakdown by disability. The government HMIS system should include this type of questions so everyone can see if a major chunk of the population is neglected or not. And the questions about why the group is not accessing services can be asked."*

D. What are the expectations of 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?

> *Central Findings:*
>
> - Data on people with disabilities is necessary for programme planning and monitoring;
> - Good quality data and documentation are essential in order to inform project management;
> - Learning from this project is crucial for project management and advocacy;
> - The data collected must be used in order to make the process meaningful.

Data on people with disabilities is necessary for programme planning and monitoring

Policy/decision makers expect to be able to know the number of people with disabilities, their type of disability/impairment, the prevalence and the geographical location so that they can tailor their programmes to meet their needs. In Tanzania the district was identified as an appropriate level to know data to as this is where projects are planned and decisions are made. In India the slum level was considered important, as in that particular project that is where decisions are made.

> *"I would like information on the scale, and types of disability in the region. Different impairments have different needs and so ideally this information would be available. Information on the extent of their awareness/ education will help plan interventions. Need to know where they live and where do they go to access services and how can we make our own services accessible to them – in terms of reach and attitude."*
>
> *"The data will help with project oversight. When we plan now we don't look at this aspect, but once we have figures that show how many people need attention a little bit more than everyone else, that will help us look at our strategies and interventions and plan for them and accommodate people with functional limitations."*
>
> *"For me in the NTD programme I would use that information to think about how many people need support and what support do they need? E.g. if many people are blind why would I use my resources for posters? It will help make tailor made IEC materials to make sure I deliver my messages to the right people with the right communication methods. The same in TT camps – the sensitisation materials should be adapted to community needs."*
>
> *"If we have a significant number of people with functional disabilities who are coming to our hospital, maybe we can start a separate counter, registration table and staff so that we can give them quicker services."*

Good quality data and documentation are essential in order to inform project management.

As this project is seen as a learning project, quality needs to be ensured at every stage of the project. Policy/decision makers expect that the data collection tool will produce good quality data. This is essential in order to have the community and the government to buy in to the whole process. Good

quality data also relies on the staff understanding and feeling ownership of the data collection tool. As a result, the training and the orientation of the data collector is essential.

> *"I expect we will have proper data. And I expect we will come to know to understand how much we are services PWDS. The barriers may be removed with proper sensitisation and training. We need guidelines and framework for each and every step and these will help minimise barrier and improve the data quality. It should be useful for research and useful for us to know who is attending our services and which services. It may help us develop rehabilitation services – so we can convince our hospital management which will show a demand for services. This will be very helpful."*
>
> *"When new things are integrated in to systems, they are often met with resistance. People may ask why if they don't see the point of the new questions. Sensitisation is therefore key and we have to have proper people selected for the project, mark the key personnel (i.e. reception level), and they require proper orientation, so they understand why we are asking those questions. There may also be resistance from non-disabled people to answer questions about disabilities who may not see the need for the questions. Proper data will only be collected of people are being asked the questions correctly."*

Policy/ decision makers also expect that every step of the process will be well documented in order to gain a good understanding of what works and what does not work and why. To do so, close monitoring and cooperation between Sightsavers, its partners and the government is expected.

> *"The only thing is we need to monitor it on a regular basis to ensure the quality of the data collection doesn't get affected over a period of time. Because it is quite possible that over a period of time you get mechanical and the sensitivity turns in to a mechanical activity so we need to ensure it is taken in the right perspective and properly used. The information is analysed and used, otherwise there is no point in collecting so much information and just keeping it in our computer."*
>
> *"I'm a bit concerned about the documentation... Quality in every aspect needs to be ensured. There are a lot of expectations from this pilot, how can we bring quality to this programme? From the first step we should ensure quality is throughout."*

Learning from this project is crucial for project management and advocacy

Another expectation is the fact that this project will gather a lot of learning on the disability disaggregation process, which will be crucial in our policy/advocacy activities.

"I expect to see quality data from this project ... The entire programme is a learning project - -by the end we will be able to understand how this project has helped in exploring how many PWDs accessed services and that way it will really help us… plus how it has helped in impacting the community and how it has impacted in the government people. Plus how the grassroots level community workers, because at the end of the day they are the ones who are going to mobilise the communities and send the people to access the services. So how their skills and their efficiency level has increased. These two things have to be at the back of the mind so that each and every step is documented so we can write a complete report of the programme we have things with us and evidence."

"I hope this will provide us with learning that can be shared and this will help Tanzania CO on the leading side to inform other partners supporting NTD and other programmes. I hope this will put Sightsavers globally in the lead on this particular issue as I know very few are doing this currently. Maybe this is too ambitious, but maybe this can generate in to a big project, the findings could achieve buy-in from other partners that could lead to other projects. I'm already thinking of education - -why not in education or eye health."

"I expect the project to be successful and to capture as much experiences and learnings as possible to inform our other programmes and projects within Sightsavers to inform our partners and the government."

The data collected must be used in order to make the process meaningful

One of the main concerns expressed by policy/decision makers involves the use of the data collected. They emphasised that once we collect this data, we have a responsibility to use it and improve the accessibly of our services, which involves scaling up once we are satisfied that the process is working.

"We need to understand the issues to understand which are within our capabilities to change and which may be beyond our capabilities but which we could advocate for. Whatever we come up with I hope it will be beneficial to the communities."

"Eventually this should become the general information that is asked. Disability shouldn't be seen as extra but a normal demographic category alongside age, gender, etc. currently seen as challenging, but the sensitisation and awareness are the main barriers. Also maybe the inclusion efforts are quite limited, but if the post-2015 agenda will address this then the country will take it up - a global force may push the issue. Political will."

"We will also learn the mechanism of collecting this information. What I would really expect to know how we are going to use this information. Many people are collecting lots of data, but then utilisation purposes have to be very very clear after that."

"Eventually I think maybe this can be done in all health facilities to help us identify the disabled in all health facilities – every person who comes to the hospital can be assessed for his or her disability. You cannot tell from looking at people if they have a disability or pain unless you ask."

Experiences of staff involved in the data collection process

Q. How can the tools and processes currently used by staff to collect client data be best adapted to include disability data?
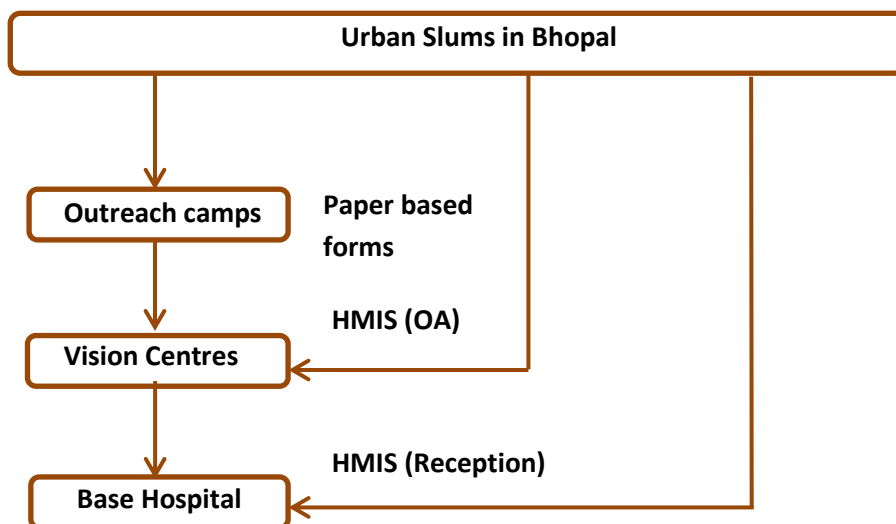
> *Central Findings:*
>
> - Questions are best integrated in the demographic section of the data collection tool;
> - Integration of the questionnaire in paper based system is more complicated due to format and cost implications.

Questions are best integrated in the demographic section of the data collection tool

In both projects, staff presented the currently used tools and identified the demographic section as the appropriate place to add the extra six questions.

In Bhopal the new Urban Eye Care Project was in the process of developing its new HMIS and so including the questions in the software was a relatively simple task involving the project managers designing the paper based forms for the software designers to then work from. In this project data is collected at three levels: community outreaches, vision centres and the main hospital. Outreach data will be collected in paper forms and later input in to the online system in the vision centre by the Ophthalmic Assistant (OA). At the vision centres themselves the data will be entered directly on to the HMIS using the laptops available in the 4 centres (see figure below).

Integration of the questionnaire in paper based system is more complicated due to format and cost implications

In Tanzania, the project focuses on two activities TT surgeries and MDA. For TT surgeries, the process was quite straight forward and it was decided to add the questions to the demographic section in the paper form. Nevertheless, decision makers were concerned that forms might get lost. The adaptation of the tool was more complicated for MDA. Data collection is currently done using a paper register book. However, the book is already quite big and reprinting it will add costs to the project and make it bigger and as a result not very practical. NTD partners put forward the idea of collecting the data using mobile

phone technology, a pilot already took place in Tanzania and the phones are currently available, only the questionnaire needs to be added to the software.

"It would be better to have a ledger or register book instead of the forms we currently use for TT surgeries. It would be less likely to be lost – it will always be there instead of these forms which we have to find files for."

"The tools will require a lot of changes and for the MDA in particular. It was easy for TT, but it will be more complicated for the MDA registers - just the tool and the understanding and the timing because it's an addition."

Project management

UK office capacity

At the start the project was mainly managed at HH level by the Research Associate and Monitoring Officer. If the initial stages of the project did not require too much work (approx. 20% of total workload), the planning and implementation of the pilot phase required more involvement of the two UK-based staff, around 50% of each of their time. Tasks such as meeting with COs to develop and finalise the proposal and budget, preparation of the training, drafting of the evaluation plan and guidance were time consuming.

Two five day trips took place in each CO in order to present the project to the staff, partners and data collectors as well as orient them on the WG questionnaire. As the understanding of disability is highly dependent on the local context and cultural factors, the importance of the consultation week should not be underestimated and training was specific to the country. This project also requires close monitoring and as a result monthly meetings are taking place with COs and mid-term review visits will be held. A final evaluation will also be organised in the summer 2015.

Due to the interest of external stakeholders, there is now a stronger involvement of the Policy and Advocacy team. If we start scaling up the pilot project, the project will require more involvement from the cross department project team, especially the Programme Development Advisors.

Country office buy-in and capacity

Country Office

Even though all Sightsavers' programme strategies need to emphasise the inclusion of people with disabilities as part of the planning process, there are still some disparities among COs.

In India, the Project Manager, Country Director and local partners are working closely together on this project. The Indian Research and M&E teams also dedicated a member of their team to this project. This project being new and focusing on a slum area, it was a great opportunity to integrate disability disaggregation of data. Moreover, the CO is keen to advocate with the government and promote this initiative as part of World Sight Day.

The NTD project in Tanzania is more focused on the elimination of NTDs and disability is not an articulated aim of the project which makes it more challenging to integrate disability disaggregation. Due to reorganisation at the CO level, three Project Officers are currently involved in this project depending on workload. The Country Director is not directly involved and has a project oversight role. The TT camps are taking place in a remote region of Tanzania, not easily accessible from the CO. This has been identified as a potential challenge for M&E activities.

Partners

Indian Partners were very involved during the consultation week, including participation in the pilot testing in the slums and the running of training session. Despite initial concerns, members of staff and partners on the ground are totally on board with the project, have a strong understanding of the project and why it is important for us to collect this data. One of the partners has considerable experience with other donors working on disability and has a strong understanding of inclusion and disability.

In Tanzania, National NTD partners exhibited a less detailed understanding of the project. However, they requested a strong involvement in the monitoring activities and understand the importance of documenting the process. Moreover, Sightsavers has one member of staff running the project who is based in the Ministry. Regional partners' are running the TT camps where the data is collected. Their understanding of the process is less developed than those of the Indian partners - as they are asked to only focus on Trachoma - but strong enough to ensure the good running of the project.

> *"As NTDs at the moment has not directed us that we have to care for PWDs... we just provide services as if everyone is abled because the programme itself goes from house to house."*

Stakeholder buy-in and capacity

This project is attracting a lot of attention from different stakeholders. Disability disaggregation is a fairly new initiative and the recent push from the post 2015 HLP and DFID means that more organisations are looking at it. Sightsavers sees this project as a learning process and is very open and honest about the challenges that come with collection of data on disability. We have identified three types of stakeholders:

Internal stakeholders

This project initially started as a small pilot but is becoming more high profile; it now includes a wide range of Sightsavers' staff from different departments (Communications, Policy and Advocacy, Research, M&E) as well as COs who are interested. This project therefore requires cross departmental collaboration. The Communication team assists us to publish regular updates on the policy blog whilst the Policy team focuses more on advocacy activities with the government and external stakeholders. The M&E and Research teams are leading on the project to ensure that the process is well documented and we can learn from it. The Social Inclusion PDA currently developing the Social Inclusion Strategy is also a key stakeholder. In order to scale up the project, new funding will have to be identified and we will collaborate with the Fundraising team.

External stakeholders

Other organisations and universities are already interested in this issue and we are actively sharing learning with them. If some (WaterAid and University of Sydney) are ahead of us and provided us with useful information on the process, most organisations are just starting to look at disability disaggregation. There is a strong will from all actors in the sectors to share and learn from each other. Organisations working on disability are starting to look at this issue and we expect that more will. We are using forums such as Bond Events and the IDDC to communicate on this project and share learning.

External targets

One of this project's aims is to advocate for disability disaggregation of data as a process and encourage other organisations to start doing it. By being involved in different forums and sharing learning, we are hoping to reach other organisations and encourage them to disaggregate their data by disability. With push from the post 2015 HLP and DFID's response to the IDC Disability and Development Report we expect that other organisations and forums will be interested in this issue.

Data collection staff buy-in and capacity

The training of the data collector is essential to ensure that they get a good understanding of the project and ultimately buy-in to the questionnaire. We noticed differences in the participation from data collectors in the two countries that may reflect cultural differences and / or language limitations; although both training sessions were conducted in English with supplementary translation provided from CO staff. This should be addressed by conducting future training in local languages only.

Data collectors and community volunteers in India were very keen on the project. They showed a strong understanding and were very proactive during the training. Disability disaggregation was also integrated in the action plan of the community outreach volunteers which was an unexpected outcome of the sensitisation activities that we conducted. In Tanzania, the medical background of data collectors proved to be an obstacle and the training had to be more focused on accessibility and limitations rather than disability.

Following the training of data collectors on the WG questionnaire, pilot testing of the newly designed data collection tool took place. At the end of the testing, focus group discussions were conducted, asking data collectors their feedback on the data collection tool.

During the consultation weeks, the following challenges were identified:

Social Model of Disability

Generally the social model of disability was poorly understood by data collectors. Our decision to use the WG short set of questions which is based on WHO's International Classification of Functioning and represents a very functional understanding of disability through enquiring about difficulties in basic daily activities may cause some confusion among staff with a very medical idea about what constitutes disability. Following the training in India, the training materials were adapted to strengthen the link between accessibility to programmes and functional limitations and remove the perceived paradox of the definition of disability. This will remain an issue in India where the national definition of disability requires medical certification and diagnosis is linked with financial benefits and in Tanzania where, culturally, disability implies a medical condition. It has been suggested that some of the confusion could be removed by changing the name of the project or standardising all project documentation to reflect our interest in functional limitations, rather than disability. Moreover, it is possible to envisage training with little focus on disability, simply providing explanation on how to conduct the interviews to avoid the confusion between medical and social understanding of disability raised above.

Translation/Understanding of the questionnaire

Because the WG questions had not yet been used in India we spent time during the training session to translate the questions to Hindi. The translated questionnaires were pilot tested in slums the next day which led to revisions. We found this exercise worked very well and seemed to allow for an element of ownership by the data collectors over the questions. The opportunity to revise them following the short pilot was important as several issues arose. Conversely in Tanzania, all except one question had previously been translated by the National Bureau of Statistics for the 2012 Census. However there may be issues with the understanding of the translation as, following the piloting, data collectors reported having to provide extra explanation especially around the communication and remembering questions (they appear to be particularly hard to translate in both languages). Moreover, the use of local language

is important in both countries which means that it is sometimes necessary to elaborate on the question further. Limited levels of education have also been identified as a barrier to understanding as some concepts are more complicated than others. In India, standardised examples were added to these questions in order to facilitate understanding in a consistent manner. We will continue to monitor this using the tools designed to collect the experiences of staff in using the tools.

> *"[Revision] May be in communication as you said to deliver message and receive, others understand that they deliver message to a certain place, therefore it had to be one way which means it had to go somewhere with a message."*
>
> *"For me the exercise of interviewing patients was a bit difficult because when you ask a patient the questions that are already in a questionnaire they need more clarifications. Hence you not only have to ask a question but also you need to further clarify it. This shows that, there is difficulty in understanding those questions to some of the patients. There are some of the people that can easily understand and there those who need clarification."*
>
> *"For example the issue of stairs many people do not understand because village stairs are conceived as ladders to climb into the ceiling store but not stairs to go inside."*
>
> *"It was felt that examples would be helpful for each of the questions plus an initial explanation at the beginning of the questions, to help contextualise it for people answering the questions."*
>
> *"People in this region are from Ndendeule and Makua tribes, when you know Ndendeule language is fair but Makuo is very difficult to understand, it requires finding a person that can elaborate in their language."*
>
> *"Personally I see the translated questions can be properly asked to a person who is conversant in Swahili, does not find it difficult and does not need examples but the one who is less conversant with Swahili then he/she needs elaboration."*

Self-reported disability

The notion of asking clients questions and recording the answer they provide, without the interviewer providing input or exercising his/her own judgement was relatively challenging to some participants in the training. Some people felt that people may lie, exaggerate, or simply not know how to answer and that they were better placed to decide on behalf of the individual. This issue arose particularly strongly when working with medical personnel. The training may have to be adapted to strengthen the idea of client perceptions of their own disabilities.

Additional Workload

Regarding the capacity, in both countries concerns about the additional time it would require asking the questions were raised. In India partner staff were particularly concerned about collecting the data in a busy hospital outpatient department environment where reception staff spent only a few minutes with each patient. These concerns were somewhat abated following the pilot testing where staff observed it

took only a few minutes to ask each patient the questions. It was also observed that with practice, asking the questions and recording the responses becomes easier. Similar concerns were raised in Tanzania, this time by the data collectors themselves who in the case of this training were a team of TT surgeons, already practised in recording data for the camps they participate in. Following the pilot session some concerns were abated, although it seems that data collection may take longer in the Tanzanian setting than the Indian, for a number of reasons including that not all clients will understand or speak Swahili and data collectors will rely on local translators.

"I see it is simple because when you ask a question and answered you just encircle the answer; therefore it is simple for use as working tool because you do not need to write another thing than encircling."

"I think this is good service and as we will continue to do it we will see how easy it becomes. Now it seems to be difficult because we are just starting. Other thing to insist is, as we know that TT is our goal therefore there are others who have trachoma problems you trace and follow them even those with disability and make friendship. Therefore, they see that we care for them and we do not discriminate anyone in the community."

"I see that I am in a negative side; this information takes long time while we are targeting to do TT surgery. Now that the information takes long time and we take long time to ask question and the patients we targeted for TT take long time instead of doing it fast to get TT patients and are being treated in time. But for long term impact it has advantage because we get to know other problems which we did not target to solve during TT surgeries."

In order to assess whether or not extra resources were needed, it was decided that two data collectors will be hired in India to help with data collection in two vision centres out of four. This is a good opportunity to assess whether or not extra resources are needed to collect this extra data.

Factors to consider when training decision makers, partners and data collectors on disability disaggregation

The training of the data collectors, partners and project managers is crucial to ensure that they get a good understanding of the questionnaire and buy into the process. Our experience highlighted the following necessary factors:

- Carrying out training in local language;
- Performing activities such as translation of the questionnaire in local language and pilot testing of the questionnaire as part of the training;
- Adapting training content to the local context and national definition of disability;
- Limiting reference to disability and instead refer to difficulty in functioning to reinforce the link between accessibility and functional limitations;
- Developing a clear advocacy plan to promote the project to the government.

Communications

Communication is also an important part of this project. We are regularly publishing articles on the policy blog to share our experience of the pilot project. We have also established a stakeholder map to ensure that we are communicating with the stakeholders identified above at appropriate intervals.

National Census Data

In both countries, extra questions were added to the six questions of the WG questionnaire in order to allow us to compare the data collected with the national census. In Tanzania, we decided to add the question on albinism as it is relevant and is a condition that could prevent people from accessing our programmes.

Tanzania

In Tanzania, the 2012 National Census had 7 questions on disability – including 5 (seeing, hearing, walking, self-care, concentrating/remembering) from the WG questionnaire. Questions on albinism and other disabilities (such as cleft palate, spinal bifida, spinal cord injury, mental health and psoriasis) were added. In Ruvuma, the region where we are carrying out the TT surgeries; the prevalence of disability is as follow:

- Albinism: 0.04%
- Seeing: 1.5%
- Walking 1.2%
- Remembering: 1%
- Self-Care: 1%
- Other disabilities: 0.30%

It is interesting to note that even employing the WG definition has revealed relatively low number of people with disabilities in the Tanzania census. There are several reasons how these unexpected results may have come about. Firstly, we do not know the severity cut-off used to define disability by the analysts and they may have used a very strict definition, involving only the higher levels of difficulties. Secondly, the questions used in the census were not exactly as recommended by the WG which may affect interpretation. Thirdly, the census included the five questions without the recommended preamble and after a section of questions focused on medically-defined disability, which may have undermined the objective of avoiding stigmatising language and focusing respondents on their health related limitations. We are following up with the national Bureau of Statistics to better understand this data.

India

In India, the 2011 National Census contained a filter question to ascertain disability status (is this person mentally/physically disabled). It attempts to collect information on eight types of disabilities ('seeing', 'hearing', 'speech', 'movement', 'mental retardation', 'mental illness' and 'multiple disabilities'). According to the census, in Madhya Pradesh the percentage of people with disabilities is between 2.01 and 2.25%.

Conclusion

Following the training of Sightsavers and its partners on the WG questionnaire and the adaptation of the collection tools, the collection of data disaggregated by disability is now ready to start. This project being a learning project, we have put together a strong M&E plan which should provide us with qualitative information on the disaggregation process. As highlighted by this baseline report, the initial stages of this project are crucial. Interviews of policy/decision makers as well as focus group discussions with data collectors provided us with important information that will inform future projects. The mid-term review which will take place early next year will also be a good opportunity to assess how the project is performing.

Decision makers and partners unanimously agreed that it is currently impossible to determine whether our projects are accessible due to the lack of data on disability available. In that respect, they found that the WG definition is useful as it articulates the issue of access to programmes and limitation in functioning. Having data on disability will allow decision makers to design their programme to ensure accessibility and monitor it. The integration of the questionnaire in the tool appeared to be more complicated in paper tools as it leads to bigger format and increased cost. Ideally, the disability questions should be embedded in the data collection tool at the start of the project. Moreover, electronic formats can easily be adapted and allow more flexibility. However, most of Sightsavers' Programmes are currently using paper based tools.

Both induction trips revealed interesting findings and challenges. Disability is a notion highly dependent on contextual and cultural factors and in that respect, training should never be neglected. Moreover, materials should be context specific and translated in local languages. This project is being piloted in two COs with very different features and resources available, which is interesting from a learning perspective. Internally, we increased the involvement of the Policy team to match the growing interest of external stakeholders. If this project is to be scaled up, more resources will have to be allocated, including social inclusion specialists and fundraising.

Next steps

- Produce a Policy Brief describing Sightsavers' current position on the collection of data on disability from among our projects for better external dissemination.
- Develop and publish a new blog post for the website.
- Identify a new name for the project that addresses the concerns outlined in the report.
- Review new project opportunities and future research questions.
- Share updates and learning with internal stakeholders identified during the Annual Programme Meeting.
- Plan projects mid-term reviews.

Appendices

Appendix 1: MPUSP Proposal - India

India Proposal – Disability Disaggregation Project

1. Project identified for disaggregating data by disability
Please identify a project which would be suitable for disaggregating data by disability.
Project name: MP Urban Slum Eye Care Programme **Project number**: 62226 **Start/End date of the project**: 1st October 2013 to 31st December 2015 **Donors**: Unrestricted fund allocation **Partners**: AARAMBH (Advocacy for Alternative Resources Action Mobilisation and Brotherhood) **Project Officer**: Jayashree Kumar

2. Suitability of the project identified for disaggregating data by disability
Why do you think this project is suitable for disaggregating data by disability?
1. Implementing this initiative into this programme would be easy as this project is a new project. 2. This project would be developing the complete MIS into which the Washington Group questions on identifying persons with such limitations can be embedded easily. 3. The HR structure can be developed in order to cater to collection of disability disaggregated data. 4. Learning from this project can be scaled up across all new projects.

Please specify the geographical focus of your project.
The project will be implemented in the Bhopal District of Madhya Pradesh (MP). Bhopal City, the capital of MP is one of the biggest and fastest growing cities of the State with a population of 2,371,061[1] covering a gross area of 285 km². This city is the administrative and political nerve centre of the State. 14% of the growth of population in this district is from the migration, mainly due to the industrial development and educational establishments in the city. The economic base of Bhopal City mainly depends on Industrial Sector, while the service sector is becoming increasingly important which provides the majority of employment in Bhopal. The city is divided into two major areas, the old and the new city. Minority religious groups together comprise close to 26% of the district's population. In terms of their population share, Muslims constitute the principal community among the religious minorities of Bhopal and they are largely concentrated in old city. The district is highly urbanised with nearly 80% of its population marked as urban; it also has a sizeable chunk of the population residing in villages many of whom retain their rural characteristics. An estimated 32% of the urban population in Bhopal lives in slums. Of these a majority of the population lives in semi-permanent or temporary houses. It is estimated that there are more than 400 slums in Bhopal. Many of these slums are inhabited by poor people mostly from rural and tribal areas from nearby districts of

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[1] http://www.census2011.co.in/census/district/311-bhopal.html

Bhopal.

With regard to the disabled population in Bhopal, according to census 2011 data states that there are around 84,502 persons with disability (males- 46,820 and females-37682) and out of them 80% are in the urban areas.

Please describe the objectives of your pilot project regarding disability disaggregation.

The objectives of this project are to:

- Design a project MIS that integrates the Washington Group disability questions and develop processes supporting its use;
- Train staff to complete the MIS including the disability component;
- Collect and analyse project data disaggregated by disability;
- Gather qualitative and quantitative evidence assessing the above project objectives in terms of:
  o User perceptions of understanding and administering the Washington Group questions;
  o User perception of the MIS training component;
  o User perceptions of the usability of the MIS including efficiency, time and cost implications;
  o Project manager perceptions of the usefulness of the data they receive and the resources expended to achieve it;
  o Client perceptions on the administration of the Washington Group questions
  o Whether disability disaggregated data meets data quality standards

Please indicate any indicators for measuring success.

- Proportion of people examined who have disability;
- Proportion of people with disabilities coming to the facility / People with Disabilities according to national census.

Please indicate what indicators/outputs will be disaggregated

- Number of People with Disabilities examined at the primary level (includes screening at the outreach camps/school screenings/vision centres);
- Number of People with Disabilities examined at the secondary level(Includes screening at the base hospital);
- Number of children with disabilities examined at the primary level (includes screening at the outreach camps/school screenings/vision centres);
- Number of children with disabilities examined at the secondary level(Includes screening at the base hospital);
- Number of treatments received by People with Disabilities;
- Number of People with Disabilities undergone surgeries;
- Number of People with Disabilities attended awareness sessions/events;
- Number of project staff trained on capturing disability disaggregated data;
- Number of People with Disabilities trained as eye care ambassadors;
- Number of community stakeholders sensitized on disability.

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

Please note that the project team will also be involved and assist you in the evaluation of the project

- During the implementation phase of the broader project, mid-term reviews and end term evaluations of the programme will be undertaken.
- The findings would provide a good opportunity 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.
- It would also provide learning experience: sustainability and impact would be assessed and outcomes and successes of the project will be documented.

The processes used for disability disaggregation will also be evaluated at each stage to ensure that enough learning is gathered, using the following means:

- In-depth interviews or focus group discussions with a variety of stakeholders at different stages of the project including design, training and implementation using the MIS. Here we will seek to document the actual experiences of the participants in the various stages of the project and any hopes or concerns they have.
- Staff responsible for asking the Washington Group questions, completing the MIS, and aggregating data throughout the MIS system (from community to partner/ Sightsavers level) will keep regular diaries of how the implementation progresses – noting in particular any misunderstandings, difficulties in administering the questions or problems it causes in other parts of their work, for example, taking too long to complete. This will allow us to understand the additional burden in terms of time and cost that is brought about by collecting this data.
- A sample of project clients will be asked a brief questionnaire at the end of their visit to the centres to understand how they found being asked the Washington Group questions, to understand any limitations or concerns about the questions and process from the client point of view.
- Data will be audited for quality by examining completed original records for correct completion, and by comparing primary compilation of original records against the consolidate data passed through the MIS processes. This will allow us to understand if the process is effective in collecting the desired data.

These evaluation activities will be planned in greater detail, including an analysis plan prior to the development of the MIS.

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

The total budget for this project is 811000 INR, approximately 9527 GBP.

The detailed budget is attached in excel format.

Sightsavers

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

Activities	Main Responsibility	Timeframe for activities –May 2014 - April 2015											
	Lead	May-14	June	July	Aug	Sept	Oct	Nov	Dec	Jan-15	Feb	March	April
Appointment of Data entry co-ordinators	Partner	X											
MIS development	Sightsavers/Partner	X											
Capacity development of project /hospital staff	Sightsavers		X										
Data entry	Disability Data coordinators		X	X	X	X	X	X	X	X	X	X	X
Sensitization of community stakeholders	partner		X	X	X	X	X	X	X	X	X	X	X
Advocacy with Government	Sightsavers/partner		X	X	X	X	X	X	X	X			X
Monthly review of the project	Partner		X	X	X	X	X	X	X	X	X	X	X
Quarterly review	Sightsavers/Partner				X			X					X
Evaluation of the project	Sightsavers							X					
Annual Review	Sightsavers/Partner								X				X

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

Support will be required from the technical agencies while developing the project MIS and documentation of the project outcomes.

Please explain why four coordinators need to be hired to manage an extra six questions (Washington Group questions) in the OPS register and the impact this would have on the sustainability of the project.

The project will be establishing four **vision centres** at different project locations once the slums are identified for intensive intervention. The project will also provide eye care services to remote locations and reach needy people of the area through **Mobile Vision centre services**. These vision centres will be functional with 2 staff- Optometrist and Ophthalmic assistant. Both would be responsible for managing the OPD and screening of patients accessing services at the vision centre and outreach camps. These staff involved with initial screenings and refractions at various service locations may not be able to fill in the required data in the OPD registers/MIS.

It was initially proposed that four data coordinators would be appointed at each vision centres and primarily their role would be to maintain the OPD registers and enter the entire data including People with Disabilities data in the project MIS. It is also planned to involve them in counselling of OPD patients including People with Disabilities as they encounter a range of attitudinal, physical and systemic barriers when they attempt to access health care or any other services.

As two partner hospitals have expressed an interest in the project and are willing to provide their staff to support the project, it was agreed that only two data coordinators will be hired. They will be appointed to manage data collection in the vision centres where partners' are unable to provide support. Members of staff who are able to support the project will be trained to administer the questionnaire. This will be a good opportunity to assess the additional workload and time necessary to administer the questionnaire by hospital staff and determine whether or not data coordinators should be systematically considered.
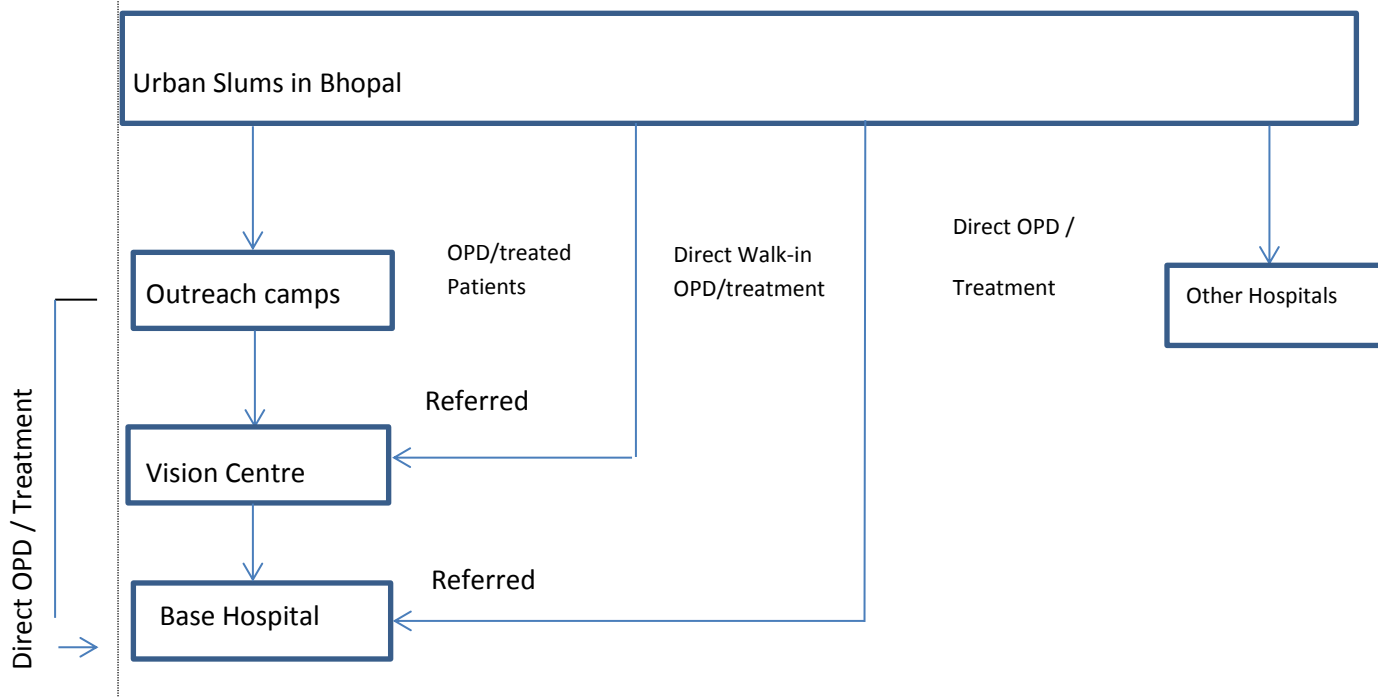
3. Data collection method

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.

Currently, the MIS has not been developed for this project and therefore data collection has not yet begun, being a new project.

The project plans to embed these questions into the new MIS by including the six questions into the Out Patient registers by adding 6 new columns with the options mentioned on the head of each column in each page. Since each patient would be asked basic questions like name, sex, age, place of residence, these additional questions would be added for each individual coming to the Vision Centres, outreach camps and the base hospital. The data will be captured from the service outlets as mentioned in the flow chart:

3. Data collection method

Flow diagram: Urban Slums in Bhopal branches to Outreach camps, Vision Centre (via OPD/treated Patients and Direct Walk-in OPD/treatment, Referred), Base Hospital (Referred), and Other Hospitals (Direct OPD / Treatment). Direct OPD / Treatment arrow leads to Base Hospital.

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

The collection of disability disaggregated data would help to assess whether People with Disabilities are left behind or if they have received proper opportunities and access to these services. The data will be shared with the project and hospital staff for better programme planning and implementation. Community people, including People with Disabilities, will be involved in understanding the findings of the data collection for community support & ownership.

The success of the pilot project would be widely shared with Government, DPOs, different forums and other sectors which would be helpful in addressing the challenges of People with Disabilities while accessing health, education or livelihood services. It would also provide a basis for policy and programmes and for efficient allocation of resources for disability disaggregated data collection and research.

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.

1. The data collected from these registers would be entered on a daily basis into the computer using statistical software like EPI info or by means of MS Access making it easier for compilation and analysis.
2. Persons asking these questions who would be placed at the Out Patient registration counter and the persons managing the project would be trained on the use of these questions using the protocols and details provided by Centre for Disease Control.
3. The entered data would be analysed monthly to find out what percentage of persons reporting at the counters have any of the limitations. This would be a part of the month regular reporting and also a part of the annual reports especially the APRs of Sightsavers. This additional

4. Management of disability disaggregated data

information would be given as add-on to the existing KPI.

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?

Currently the India Government is collecting data on disability nationally through census and sample surveys conducted by the Census Department of India and the National Sample Survey Organisation respectively.

The following are the questions which were asked in India for the National Census 2011:

9(a) is this person mentally/physically disabled?

- Yes – 1
- No – 2

9(b) If '**YES**' in 9 (a), give code in the box against 9 (b) from the list below:

- In Seeing – 1
- In Hearing – 2
- In Speech – 3
- In Movement – 4
- Mental Retardation – 5
- Mental Illness – 6
- Any other – 7
- Multiple Disability – 8

6. Risk Assessment

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

There is no perceived risk to collection of disability disaggregated data, though the initiative runs the risk of subjectivity which is usually the case with such questions. This risk can be mitigated by proper explanation of each question, its limitation through training to the project staff who would be implementing this.

Appendix 2: Ruvuma NTD programme proposal - Tanzania

Tanzania – Disability Disaggregation Project

1. Project identified for disaggregating data by disability
Please identify a project which would be suitable for disaggregating data by disability.
Project name: Tanzania NTD (Trachoma, Onchocerciasis & LF) /IANET **Project number**: 24008 **Start/End date of the project**: May – March 2015.   . **Donors**: FHF support for Trachoma interventions up to 2013. No communication for restricted funding in 2014. Other interventions are funded through unrestricted funding. **Partners**: Ministry of Health and Social Welfare- NTD Programme, Ruvuma Regional Authority, Tanzania League of the Blind   . **Project Officer**: Janeth Bushiri.

2. Project information
Please specify the geographical focus of your project.

Sightsavers in partnership with Ministry of Health and Social welfare implements the IANET project. Sightsavers supports the treatment and prevention of both Trachoma and Onchocerciasis alongside Lymphatic Filariasis. Currently the programme focuses on communities covering two main components:

- An integrated approach for all 5 diseases in 2 districts of Morogoro rural, Mvomero in Morogoro region, Eastern central Tanzania and;
- SAFE strategy implementation for elimination of Trachoma in 7 districts of Tunduru and Namtumbo districts (includes bordering villages for Songea Rural district) in Ruvuma region, Kiteto and Simanjiro districts in Manyara region, Monduli, and Longido districts in Arusha region; other NTD interventions related to Community engagement, and coordination in Zanzibar Island.

For the purpose of this pilot project on Disability Disaggregation, it is expected the geographical coverage for TT surgeries and MDA will be in Namtumbo District in Ruvuma region:

- About 4 outreaches covering 6,000 people for screening and 200 for TT surgeries.
- **MDA** will be limited to two villages of Rwinga and Mandepwende having a total of 40 CDDs.

Please confirm when the Mass Drug Administration takes place in the project location.

At community level:

- **MDA** takes place from October to December. The schedule sometimes may vary due to timely availability of funds from the partner, or delays in drug logistics.
- Morbidity interventions (**TT surgeries**) take place throughout the year on quarterly basis.

As MDA takes place in October, two options are currently being considered:

1. Start disability disaggregation earlier for TT surgeries only and carry on with MDA in October.
2. Start disability disaggregation for TT surgery and MDA at the same time in October.

The first option has been chosen. It allows us to start data collection earlier and we will be able to present some progress at the annual meeting. It is also a good opportunity for the Tanzania Country

Office to gain experience of disability disaggregation as it is considered to be 'easier' to collect disability disaggregated data for TT surgeries than MDA. However, it will also require dividing the training into two sessions. Support will be provided for the first round of data collection and it is expected that the Tanzania Country Office will require less support for the second round of data collection with MDAs.

Please explain why this project is particularly suited for disability disaggregation of data.

The project suits disability disaggregation because it covers the whole population in the project area where disability group are also covered. The project has a very huge component of engaging the community through **MDA** where details for all eligible family members are captured and there is a well-established system of information flow.

Additionally through **TT outreaches** huge number of people are screened and offered treatment and surgeries. As a result the project covers huge population.

This project is of significant importance in the development sector ever since according to contemporary models looking at disability as a stand-alone component. Uniqueness of this project is manifested in a way disability is regarded as an integral part of community life and development work. Disability has to clearly feature in all interventions and data to measure success.

Please describe the objectives of your project regarding disability disaggregation.

The objectives of this project are to:

1. Design a collection tools that integrates the Washington Group disability questions and develop processes supporting its use;
2. Train staff to complete the WG questionnaire;
3. Collect and analyse project data disaggregated by disability;
4. Gather qualitative and quantitative evidence assessing the above project objectives in terms of:
   a. User expectations of the benefit of disability disaggregation
   b. User perceptions of understanding and administering the Washington Group questions;
   c. User perceptions of the collection tool;
   d. User perceptions of the usability of the collection tool including efficiency, time and cost implications;
   e. Project manager expectations and perceptions of the usefulness of the data they receive and the resources expended to achieve it;
   f. Client perceptions on the administration of the Washington Group questions;
   g. Whether disability disaggregated data meets data quality standards.

Please indicate any indicators for measuring success.

For TT surgeries:
- Proportion of people examined who have disability
- Proportion of people with disabilities coming to the facility / People with Disabilities according to national census

For MDA:
- Proportion of people examined who have disability
- Proportion of people with disabilities examined by the CDDS / People with Disabilities according

to 2011 national census
- Percentage of People with Disabilities reached for MDAs in Namtumbo district

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Please indicate what indicators/outputs will be disaggregated

- Number of TT cases conducted in Ruvuma region by 2014.
- Number of People with Disabilities received TT surgeries
- Number of People with Disabilities treated with antibiotic (via MDA)
- Number of PWDs treated for Onchocerciasis (via MDA)
- Number of PWDs treated for Lymphatic Filariasis (via MDA)
- Number of project staff oriented on integrating disability data into NTDs information system.

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

The project will be evaluated at the end of the project implementation. In carrying out evaluation, the following activities will be done;

1. Periodic review sessions will be held in order to review the performance of the project during implementation. Review will be informed by information captured and feedback from field visit which will present the qualitative insights.
2. A technical team including the project team will develop evaluation tools which will be used to assess the project achievements.
3. A consultant will be assigned to carry out the actual evaluation. Data collectors will be identified under the guidance of the consultant.
4. Data Compilation, analysis and report writing will be undertaken by the consultant in close collaboration with the project team.
5. Conduct a one day dissemination workshop to inform stakeholders on the findings of the project.

The processes used for disability disaggregation will also be evaluated at each stage to ensure that enough learning is gathered, using the following means:

- In-depth interviews or focus group discussions with a variety of stakeholders at different stages of the project including design, training and implementation using data collection tool. Here we will seek to document the actual experiences of the participants in the various stages of the project and any hopes or concerns they have.
- Staff responsible for asking the Washington Group questions, completing the questionnaire, and aggregating data (from community to partner/ Sightsavers level) will keep regular diaries of how the implementation progresses – noting in particular any misunderstandings, difficulties in administering the questions or problems it causes in other parts of their work, for example, taking too long to complete. This will allow us to understand the additional burden in terms of time and cost that is brought about by collecting this data.
- A sample of project clients will be asked a brief questionnaire to understand how they found

being asked the Washington Group questions, to understand any limitations or concerns about the questions and process from the client point of view.

- Data will be audited for quality by examining completed original records for correct completion, and by comparing primary compilation of original records against the consolidated data. This will allow us to understand if the process is effective in collecting the desired data.

These evaluation activities will be planned in greater detail, including an analysis plan prior to the development of the collection tools.

Please provide us with a detailed budget, including the cost of evaluation.

The total budget for this project is 35,833,220 approximately 14,297sterling pounds.

The detailed budget is attached in excel format.

ACTIVITIES	TIMEFRAME 2014								2015		
	May	June	July	Aug	Sept	Oct	Nov	DeC	Jan	Feb	March
Identification of Key players in the programme during disability project implementation.	▓										
Conduct stakeholders meeting to introduce the project and develop NTD based disability data disaggregation tool	▓										
Training orientation to TT surgery team on the revised tools for data collection	▓										
Data collection (disability disaggregated)/Field work during TT outreach surgeries.		▓	▓	▓	▓	▓	▓	▓			
Training orientation to CDDs and front line health workers on the revised tools				▓							

Activity	1	2	3	4	5	6	7	8	9	10	11	12
for data collection			■									
Data collection (disability disaggregated)/Field work during MDAs				■	■	■	■					
Data compilation and Reporting								■	■			
Supervision and monitoring visit during data colletcion/outreach		■		■		■		■				
Project review meeting and development of evaluation data tool						■						
Evaluation field work										■		
Data compilation, analysis, Report writing										■	■	
Dissemination of preject evaluation report												■

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

The process will need to engage experienced in-country resource persons in community development and health projects particularly those with knowledge on issues, needs and rights of PWDs. They will support to provide guidance in the process of development/review of tools, data analysis and production of final report.

Engaging with Sightsavers **Programme Strategy, Evaluation & Research** department to support designing and development of tools at the start and guidance on evaluation.

3. Data collection method

Please describe in detail the data collection activities currently taking place in this project, including

3. Data collection method

timelines and responsibilities.

The activity which is taking place currently in the IANET project includes:

- Specific tools which guides recording information of people who come for eye services during **TT outreaches**. The information includes screening and treatments. Data is then shared with district, regional authority and national office. Data collection for 2014 will start in April. Eye care personnel are responsible for treating and managing the data. The Washington Group questionnaire will be incorporated in the registers which are used in collecting information of people, as additional piece of paper in their list.

- In the project area **MDA** is supported by African Programme for Onchocerciasis Control (APOC). As a result data collection is mainly dependent on APOC support. Sightsavers community awareness and supervision during MDAs. Data is generated by Community Drug Distributors. The CDDs submit data to Front Line Health Workers where summary is compiled and shared with District level. From the district the NTD coordinator compiles data and submits to Regional NTD coordinator who then submits to National NTD office. The WG questionnaire will be included in the current data collection tools. It is proposed that a page/sheet is added to the register in order to integrate the questions.

Please specify if at facility level the data will be collected for all patients or just those visiting for NTDs?

For this project data at **facility level** will only be collected for those visiting NTDs. Although routinely the facility data is available for all patients. Some data for morbidity are collected at the facility and others from the community through outreaches/camps. Data is then compiled at the facility level for NTDs only. As for **MDAs** the facility level is responsible for compiling data which is collected by CDDs at household level.

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

- Data collection will help to uncover challenges People with Disabilities face in accessing designated services for all community members. It will then propose best approaches or thinking around service delivery.
- Such data will help to statistically analyse how many People with Disabilities benefit from NTDs intervention, whether or not there is a specific target or plan in NTDs aiming at using affirmative action for People with Disabilities.
- Results which will be obtained from analysis of such data will provide information about the situation of People with Disabilities in the context of realising the internationally agreed development goals, including the Millennium Development Goals as well as National programmes and projects.
- Analysis of disability data will provide key stakeholders with adequate insights and best practice regarding planning and implementation of development interventions as well as use of disability disaggregated data in their programmes and projects.
- Inform future design of projects

4. Management of disability disaggregated data

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.

Currently MoHSW under NTD program is managing all data that are collected in the entire regions which implement NTD activities. All data collected are aggregated into different categories like age, gender, drug type given, operations provided, geographical location and the like. The information is then analysed, interpreted and used to make decision towards strengthening programme interventions at different levels.

During implementation of this project disability data will have been collected as part of overall NTD data. Analysis will be done for different categories including disability category. At this point it will require working closely with TLB to sharpen the disability aspects.

Having put in place smooth preliminary preparations for the project, as well upon successful implementation; the project will avail information on disability on specific items and will uncover challenges People with Disabilities encounter in accessing services and opportunities of programmes available in their communities. The information will inform future planning, implementation and programme design by different stakeholders including Sightsavers thereby enhancing gradual disability mainstreaming. In the final analysis, this project will situate Sightsavers and the implementing partners as models on issues of disability mainstreaming especially on data disaggregation by disability.

5. Disaggregation of data by disability at national level

If possible, please specify the cut-off/estimate of prevalence used in the national census to identify persons with disabilities.

Questions from Washington group were reviewed to fit the country context. They were increased from 6 to 8.
Questions were incorporated into both short (this was administered to 70% of the country) and long (covered 30% of Tz population) questionnaires hence covered the whole country.
This was followed by training of trainers and then training of enumerators

The head of the household was asked questions. In case he/she was unable to explained a relevant person was called forth to explain.
The head would list all members in the family and provide their information
With regard to disability for each member of the family including the head questions were asked one by one whether the person has any problems with hearing, seeing, and all the other 6 types.

The team participated in the 2012 National Census did not have any medical expertise or equipment to support the assessment process. They only depended on the response given from the person interviewed and categorise him/her under the above categories.

Is there an indication of when the disability-related data from the 2012 census will be available?

The information from 2012 population census is already out. Please find the attachment in a separate sheet.

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6. Risk Assessment

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

The exercise of collecting disaggregated data on disability is expected to encounter the following risks:-

- Distortion of information on certain disabilities due to low awareness of data collectors on disabilities.
- Prevailing negative attitudes towards persons with disabilities by community members.
- Shortage of human resources in NTD programme might cause negligence and despair of this project.

Appendix 3. Evaluation Plan

To be answered by the pilot phase:

1. How can data disaggregated by disability be collected on a project level in a resource-efficient way that is useful to policy and decision makers?

To be answered by the disability disaggregation project:

2. How does the availability of project data disaggregated by disability impact on the accessibility of the project for people with disabilities?
3. How does the availability of project data disaggregated by disability impact programme design?

Main questions to be answered:

How can project data be disaggregated by disability be collected in a resource-efficient way that is useful to policy and decision makers?

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

Policy/ decision makers and project managers

A. How do policy/ decision makers understand issues around accessibility of People with Disabilities to projects, and how do they see data as playing a role in accessibility?
B. How useful is the definition of disability provided by the Washington Group to policy/ decision makers and how does it complement their own understanding of disability?
C. What are the views of 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?
D. What are the expectations of 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?
E. What are the views of project managers on the sensitisation/ training provided to their staff and how do they perceive it has affected the way they conduct their work?
F. How useful is the data provided by the data collection system to the work of policy/ decision makers and is it to the correct level of detail?
G. How has the data collected to date been used in any way by policy/ decision makers?
H. How does the appropriate data collection methodology and technology impact on the quality and timeliness of the data available to policy/ decision makers?
I. What data would policy/ decision makers like to have access to that remains unavailable?
J. How have policy/ decision makers integrated any aspect of this project in to other project over which they have control, including disability awareness and collecting data on disability?
K. How have different partners collaborated on this project and what impact can they attribute to partnership working?
L. 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

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

O. How do staff collecting/ analysing the data understand the purpose of data disaggregated by disability and how can the training best orient them to understanding the importance of accurate data collection?

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

Q. How can the tools and processes currently used by staff to collect client data be best adapted to include disability data?

R. How do the tools and guidelines developed specifically for this project fulfil their purpose and how could they be improved?

S. How does the appropriate technology, including hardware and software, impact on how staff are able to collect and analyse data?

T. 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?

U. 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?

V. 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?

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?

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?

Project clients providing the data

Y. How do project clients comprehend the questions as they are asked to them?

Z. How do project clients feel about being asked these questions?

AA. How do project clients understand the reasons for the data being collected?

![Sightsavers logo]

Methods for collecting the data

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 data and what may explain the differences?	Project data collected using the agreed designed/ adapted tools. Census data as publically available online.	In quarterly reports.	Project staff as agreed in the monitoring plan.
A. How do policy/ decision makers understand issues around accessibility of People with Disabilities to projects, and how do they see data as playing a role in accessibility?	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. This work should include: • Mapping the key stakeholders • 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 • Analyse the interviews for themes and patterns. Depending on the number of interviews this could be done by hand or using a software	At the beginning and end 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.
B. How useful is the definition of disability provided by the Washington Group to policy/ decision makers and how does it complement their own understanding of disability?		At the beginning and end of the project	
C. What are the views of 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?		At the beginning of the project only	
D. What are the expectations of 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 beginning of the project only	

Question	Data collection method	When	Who
E. What are the views of project managers on the sensitisation/ training provided to their staff and how do they perceive it has affected the way they conduct their work?	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.	Halfway through the project	
F. How useful is the data provided by the data collection system to the work of policy/ decision makers and is it to the correct level of detail?		Halfway through and at the end of the project	
G. How has the data collected to date been used in any way by policy/ decision makers?		Halfway through and at the end of the project	
H. How does the appropriate data collection methodology and technology impact on the quality and timeliness of the data available to policy/ decision makers?		Halfway through and at the end of the project	
I. What data would policy/ decision makers like to have access to that remains unavailable?		Halfway through and at the end of the project	
J. How have policy/ decision makers integrated any aspect of this project in to other project over which they have control, including disability awareness and collecting data on disability?		Halfway through and at the end of the project	
K. How have different partners collaborated on this project and what impact can they attribute to partnership working?		Halfway through and at the end of the project	

Question	Data collection method	When	Who
L. How can lessons learned from this project be captured to implement this work in other projects and to share with partners and other organisations?		Halfway through and at the end of the project	
M. 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? N. How does orientation on disability issues affect the way staff interact with project clients/ patients with disabilities or impairments? O. How do staff collecting/ analysing the data understand the purpose of data disaggregated by disability and how can the training best orient them to understanding the importance of accurate data collection? P. How often do staff require refresher trainings or support to maintain high quality data collection? Q. How can the tools and processes currently used by staff to collect client data be best adapted to include disability data? R. How do the tools and guidelines developed specifically for this project fulfil their purpose and how could they be improved?	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 on a quarterly basis	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.

Question	Data collection method	When	Who
S. How does the appropriate technology, including hardware and software, impact on how staff are able to collect and analyse data?			
T. 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?			
U. 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?			
V. 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? 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 plus those involved in maintaining the data can maintain regular 'diaries' or their experiences with collecting the data. They should be encouraged to record 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. The diaries will be collected by project staff on a regular basis, collated and analysed for themes, possibly using a software package.	This should happen throughout the project and the diaries should be collected at monthly meetings	This will require one person to collect the diaries, collate the information and analyse the data contained.

Question	Data collection method	When	Who
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?	This can be checked through 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.	This could happen sporadically on a sample of data - with one or two indicators being audited every quarter.	This will require a detail orientated person to choose the indicators, trace them back and record discrepancies and note remedial actions.
Y. How do project clients comprehend the questions as they are asked to them?	A very brief survey of a sample of clients leaving the vision centres/ mobile services. • 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 client has to be asked – every second or third client leaving over one day could be asked. • The clients should be asked if they mind sparing 5 minutes to answer questions about their visit today. • The surveys could be recorded on paper or straight on to a laptop data base if it is possible to take that to the location. • The data can be analysed using appropriate software.	Quarterly at each location	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.

Outputs

An initial report can described the baseline understandings and expectations of the stakeholders and data collections staff at the beginning of the project.

Half way through a second report can summarise any data collected at that point, problems with quality gathered from the data audit, staff experiences from the diary collection, client experiences per surveys conducted at that point, plus and reactions from the stakeholders to any data they may have received at that point.

A final report should provide summary of the first two reports plus further updates on data, quality, experiences of staff and clients, plus further stakeholders and staff interviews and focus groups. This report should also include a summary of how the MP Urban Slum Eye care Programme and the organisations involved plan to progress with collecting data disaggregated by disability. It should make recommendations to other project managers interested in collecting similar data to how their projects can be best designed.