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Sightsavers' disability data disaggregation project

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Background

Data is critical for measuring progress in development; without accurate and comparable data, it is not possible to adequately plan for and allocate the necessary resources to ensure that our programmes achieve their objectives. Data is crucial for planning and monitoring who we reach; good quality and comparable data, including development indicators that can be disaggregated by factors such as sex, age and disability, are needed to ensure that decisions are not being taken that reinforce existing inequalities. The global lack of data on disability is a critical development issue – unless the gap in available data is addressed there is a serious risk that people with disabilities will be left behind.

This briefing outlines Sightsavers' experience of collecting and disaggregating data on disability in different contexts. We use the data to help build our evidence base, identify how to better collect and integrate disability data into our work, and improve the inclusiveness of our programmes. We encourage other development agents to collect and use disability data to ensure that development progress is inclusive.

The World Health Organization and the World Bank estimate that there are one billion people with disabilities globally.[1] Of these people, an estimated 80 percent live in developing countries. However, there is a global lack of accurate and reliable data on disability that allow comparisons at the global, national and local level. This risks decisions being taken that perpetuate disparities in development and exclude people with disabilities. If data on people with disabilities are not collected and used, it is not possible to measure how they are reached by international development programmes, putting them at risk of further marginalisation.

In 2015, UN member states adopted the 2030 Agenda for Sustainable Development, committing to development that leaves no one behind.[2] Agenda 2030 references disability specifically in five goals and seven targets and commits countries to disaggregating data by disability across a number of indicators.[3] To deliver Agenda 2030 and ensure inclusive development, a sustained commitment to collecting data on disability is essential. Together, development actors, including governments, multilateral organisations, donor agencies and civil society, can collaborate to promote and collect better data on disability, to fill the data gap and ensure that we use data on disability to inform better, more inclusive, development that leaves no one behind.

Opposite

A community drug distributor (CDD) measuring a boy during a Mass Drug Administration campaign to combat Neglected Tropical Diseases in Ghana.

Cover image

A social mobiliser makes door-to-door visits to inform people with disabilities about their right to vote in Cameroon.

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What we have done so far

Our first pilot studies in India, Tanzania and Malawi[4] demonstrated that collecting and using disability disaggregated data using the Washington Group Short Set (WGSS) of Questions[5] in our health programmes was feasible and generated useful information to act upon. This was a critical first step towards building our experience on collecting disability data and helped us reflect on how to improve the accessibility of our programmes and adapt the delivery of our health services to be more inclusive.

We have used the WGSS in population-based surveys to measure coverage of and access to quality health services for people with disabilities, and are combining them with other measures of equity, including sex, age and wealth, to better understand how different factors intersect to shape marginalisation.

We have built considerably on our experience of using the WGSS, which were developed by the Washington Group on Disability Statistics, an expert group put together by the UN Statistical Commission. The WGSS were designed to operationalise the International Classification of Functioning, Disability and Health (ICF) for comparable national-level disability data, and although they are not extensive, they are a good measure of disability that is appropriate for national surveys and censuses. However we also use some of the Washington Group's more detailed questions sets in other contexts, including the Extended Set of questions and the Washington Group/UNICEF Child Functioning Module.[6]

Our recent experiences of using the WGSS include:

In **Ghana**, we piloted the feasibility of collecting disability data at a large scale, where community members were responsible for data collection. We integrated the WGSS in routine data collection by Community Drug Distributors (CDDs) through a nationwide Mass Drug Administration (MDA) campaign for Neglected Tropical Diseases (NTDs, i.e.

onchocerciasis and lymphatic filariasis). Data were collected in two districts during two rounds of collection (in 2016 and 2018), from more than 170,000 people.

In **Cameroon**, **India**, **Mozambique**, **Pakistan** and **Tanzania**, we collected data on disability alongside data on wealth, age and gender in Rapid Assessment of Avoidable Blindness surveys (RAABs; a population-based survey to assess the prevalence and causes of avoidable blindness). These exercises allowed us to explore how eye health status and access to eye health services were associated with different demographic characteristics, including:

- In Nampula Province, **Mozambique**, we examined 4,015 individuals aged 50 years or over in 2018. This was the second survey to have been performed since 2011, making Nampula one of the few locations where RAABs have been repeated. This allowed us to measure the change in prevalence and causes of blindness, and cataract surgical coverage, over the two time points.

- In the **Indian Sunderbans**, we conducted a population-based survey among 3,410 people aged over 40 years to assess their health access and health seeking behaviour, as well as disability and wealth status. The data collected was geo-referenced, meaning that we were able to visually map results and identify patterns of health and access in this geographically complex area.

We also took the step to start using the questions for monitoring attendance in our programmes:

- In our Urban Eye Health project in **Bhopal**, **India** our first pilot collecting disability data using the WGSS (2014/2015) developed into an Inclusive Eye Health pilot approach (2016/2017), meaning adaptations were made to increase the number of people with disabilities and women accessing eye health services. Over its 18-month lifespan, we collected data from 39,165 people across hospitals, vision centres and outreach camps.

- In 2018, we also initiated our Inclusive Eye Health projects in **Bangladesh**, **Pakistan** and **Mozambique**, with the objective to deliver eye care services and removing barriers to access health services for people with disabilities. We have now completed collection of data on patients who accessed our services at baseline in Bangladesh (7,079 patients) and Pakistan (3,315 patients), as reference points for monitoring how people with disabilities access our services over the length of the projects.

Beyond our health programmes, we are also branching out on using the Washington Group questions sets in other contexts:

- In our political participation studies in **Senegal** and **Cameroon**, we used the WGSS to measure levels of participation of people with disabilities in national and local decision-making processes, governance institutions and political parties.

- In **Malawi**, we used the Washington Group Child Functioning Module in a study looking at disability inclusion in early childhood development and education centres.

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A surgeon examines the eyes of a patient after his cataract surgery in Sightsavers' Inclusive Eye Health project in Nampula Province, Mozambique.

What we have learned so far

Collecting disability data has revealed a number of interesting findings:

Integrating the WGSS on large scale is possible and effective training had benefits on sensitisation.

In **Ghana**, integrating the WGSS in data collection during MDAs showed that using the question set at data collection by community workers at a large scale was possible. Across both rounds of data collection and locations, the proportion of people receiving the treatment were higher among people with disabilities (91.3% – 100%) than in the total population (80.7% – 83.8%). People with disabilities had nearly seven times greater odds of receiving the drugs than people without disabilities (OR=6.9; 95%CI= [3.8-12.7]), even following adjustment for age and sex.

Our qualitative data showed that training and sensitisation had a positive influence on data collectors' and health providers' attitudes and perceptions towards people with disabilities. Throughout the project, health service providers and CDDs were able to better understand the needs of people with disabilities and the importance of equitable access to health services. Although we cannot say for sure, it is possible that this contributed to the increased registration and administration of treatment to people with disabilities.

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

Collecting disability data alongside other measures is feasible and can help explore the intersectionality of marginalisation.

In **Mozambique**, our RAAB survey revealed that the prevalence of blindness due to cataract had decreased in 2018, compared to 2011, and cataract surgical coverage (CSC) had overall improved (from 12.5% in 2011 to 31.5%). Cataract surgery with a good outcome (effective CSC), also appeared to be higher. But despite a general improvement, disaggregation of data by sex and disability revealed inequities in coverage and in access to quality services. The surgical coverage was higher among men (42%) than among women (21%). People reporting functional difficulties in domains other than sight had a higher prevalence of visual impairments than the control group, and surgical coverage was lower.

Surveys in **Cameroon**, **India**, **Mozambique**, **Pakistan** and **Tanzania** confirm that access to health services can differ by sex, disability and wealth status in different settings, and that it is important to understand the different factors at play in any particular setting. This highlights the importance of not just looking at disability in isolation, but collecting disability data alongside other relevant factors, including sex, age, location and wealth status.

How questions on disability are asked makes a difference.

Consistent with the findings from our pilot, in our Urban Eye Health project in **India**, it was reaffirmed that the way questions on disabilities are asked make a difference. In particular, women were more likely to report disabilities than men when using the WGSS assessing functionality, but
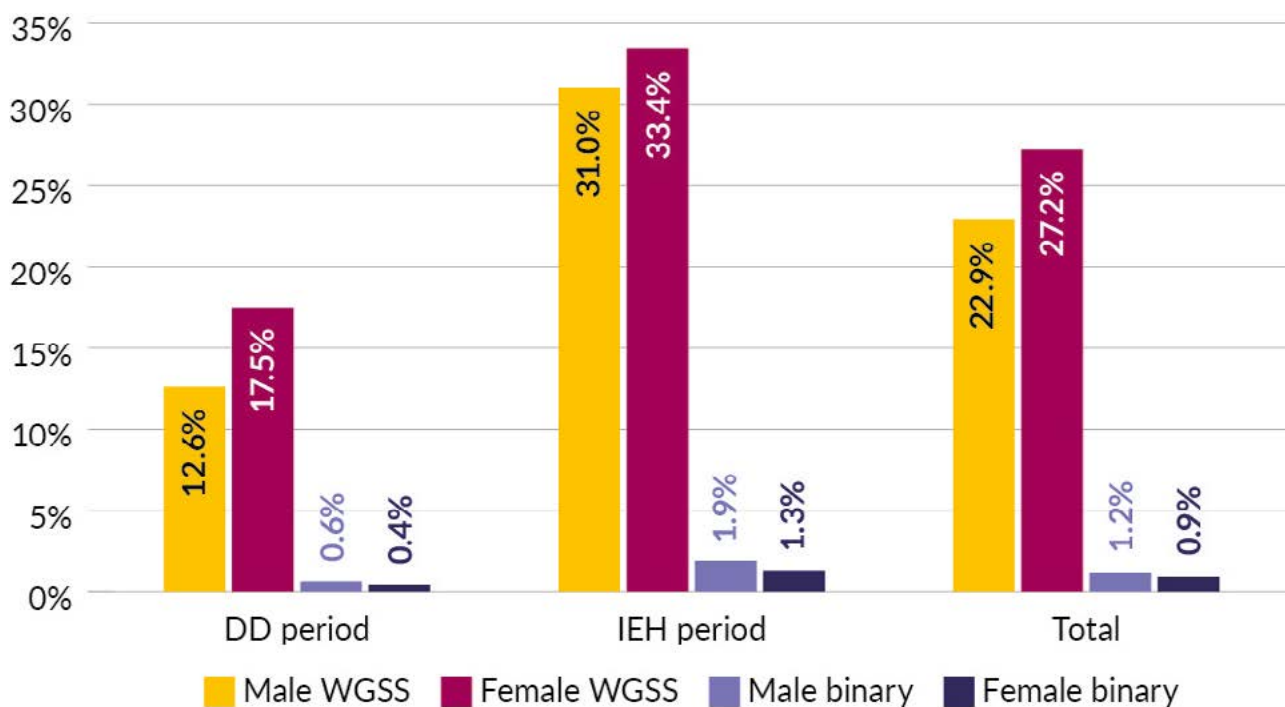
Figure 1. Prevalence of disability between men and women in different project periods, as determined by the Washington Group Short Set of Questions (WGSS) and the binary yes-no questions. DD: Disability Data pilot period (2014/2015). IEH: Inclusive Eye Health pilot approach (2016/2017).

were less likely to self-identify as 'disabled' when directly asked about disability using the binary (yes-no) measure (**Figure 1**). This suggests that references to function rather than disability could remove some of the bias due to different definitions and perceptions of disability.

Collecting disability data helps us understand the characteristics of people accessing our services.

The continued collection of data on attendees in our post-pilot Urban Eye Health project in Bhopal, **India**, revealed interesting patterns about how people with different characteristics accessed our eye health project. Women were more likely than men to attend community-based services (outreach camps and vision centres), but less likely to attend the hospital. People with disabilities were also more likely to attend community-based services. This suggested that women and people with disabilities may experience problems with reaching hospital services.

The baseline data collected in late 2018 in our Inclusive Eye Health programme in **Bangladesh** and **Pakistan** showed that in all settings, the overall prevalence of disabilities (including visual and non-visual) was 50% or over. Excluding the visual domain, prevalence of disability was high (27% in Bangladesh and 41% in Pakistan) and more frequent among women than men. The high prevalence showed that many people with disabilities were already accessing our services.

Sightsavers   7

How we are using the data

We will continue to collect and use disability disaggregated data from our programmes and draw from our experience of collecting data on other variables of marginalisation. Our experience will help us understand the intersectionality of marginalisation and to improve our approach to become more inclusive based on what we are learning. We will continue to share our learning to improve the knowledge base around marginalisation and create opportunities for decision-makers to access evidence to ensure that no one is left behind.

Our experience of collecting and using disability disaggregated data to date has allowed us to reflect on how to:

Better collect and use data

In **Ghana**, the integration of the WGSS in data collection during MDA showed that integrating the questions into routine data collection on a large scale, where community workers were responsible for collecting the data, was both feasible and had significant programmatic benefits. We will draw upon the experience and seek opportunities to embed questions such as the WGSS in other data collection activities to promote a demand for better disability data.

Our population-based surveys in eye health and political participation in **Cameroon**, **India**, **Mozambique**, **Pakistan**, **Tanzania** and **Senegal** demonstrated that collection of multiple variables of equity alongside the WGSS was feasible and useful. We will continue collecting data on factors including disability and wealth status, and design studies to develop our understanding on how different factors of marginalisation are at play in different settings.

Our findings from comparing two different methods of disability data collection in our Urban Eye Health project in India reconfirmed that people are less likely to self-identify as 'disabled' when asked a binary question (yes-no). This suggested that we should avoid making direct reference to disability when collecting data from respondents. We will continue to use the Washington Group questions as appropriate and will consider other methods that may be relevant for different research questions.

Reflect on how to be more inclusive at all levels of delivery

In **Ghana**, the positive effect that training on the questions had on changing the attitudes of health workers and CDDs towards disability and their understanding of the needs of people with disabilities was encouraging, and consistent with our reports from earlier pilots. We continue to provide training on the use of the questions and sensitisation of health workers to disability-inclusive practices in our programmes.

In our Urban Eye Health project in **India**, women were more likely than men to use vision centres and community clinics and less likely to use hospitals. People with disabilities more frequently attended community services. This indicated that women and people with disabilities may experience problems with reaching hospital services and that the availability of community-based services continues to be important for reaching these

population sub-groups. This clearly demonstrates the need to be both gender and disability sensitive at all levels of healthcare service provision.

The high proportion of people with both visual and non-visual disabilities attending our Inclusive Eye Health projects in **Bangladesh**, **Pakistan** and **Mozambique** at inception emphasised the potential benefits of ensuring accessibility and the provision of disability-sensitive services. We will use the WGSS to monitor the proportion of people with disabilities accessing our services throughout the duration of the project, using the baseline assessment as a comparison. This will be an opportunity to learn how to further improve our inclusive practices.

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A man attending an Inclusive Eye Health outreach camp in Barakoh outside Islamabad, Pakistan.

Next steps

Based on our learning so far, we now plan to:

- explore how to integrate data on disability and other factors of equity into our programmes, in order to monitor participation and need, to ensure that services are accessible to all and of the same quality.

- use other modules of the Washington Group questions, and consider other methods to measure disability, according to purpose and the level of accuracy and operability needed in different contexts.

- explore how disability data can be used in combination with other tools to understand the intersectionality of marginalisation and better identify how different factors, including disability, sex, age, wealth status and location may affect health service coverage and access to quality services.

- incorporate the WGSS in population-based surveys as a tool for disaggregating the results by disability, including in RAABs, and continue to explore other areas of our work in which they could be used, such as political participation studies.

- continue to disseminate our findings and experience of collecting disability disaggregated data, contributing to the evidence base on people with disabilities, and encouraging the use of better disability data to inform decision-making.

Recommendations

Our early experiences using the Washington Group Questions showed that collecting disability data in development programmes is both possible and useful, and provided a critical first step to improving the accessibility of our programmes. Our cumulative experience from collecting, analysing and using disability disaggregated data is demonstrating that the simultaneous collection of data alongside other equity variables allows a fuller understanding on the intersectionality of marginalisation, and can lead to more effective – and inclusive – decision-making.

It is crucial that data is acted upon. We encourage other actors to collect and use disability disaggregated data and adapt their approaches with the ambition to leave no one behind.

We recommend:

- Committing to measuring equity – including disaggregating data by sex, age, disability and wealth – and modifying approaches in order to reach populations at risk of exclusion, including people with disabilities.

- Developing a clear rationale for collecting and disaggregating data for multiple factors of marginalisation such as disability and wealth, alongside common demographic factors including gender and age.

- Promoting contextual sensitisation and training on disability and other factors of marginalisation in development programmes.

- Limiting references to disability in data collection – instead referring to difficulty in functioning – to reinforce the link between accessibility and functional limitations, and to protect against negative attitudes and discrimination which can influence the way questions are asked and responded to.

- Developing a plan for how the data will be analysed and used to inform decision-making.

- Disseminating data to help build the evidence base on disability and development, and strengthen opportunities to factor disability inclusion into decision-making.

Our experience has shown that the process of collecting data on disability can change attitudes. Collecting data on disability raises awareness and can enable health workers to prioritise the rights of people with disabilities.

Data can be used to sensitise policymakers and the wider community on the importance of accessible and disability-inclusive services. By ensuring availability of and access to accurate and internationally comparable data, we can contribute to closing the data gap on disability and promote decision-making that is inclusive.

We encourage development actors at all levels, including governments, multilateral organisations, donor agencies, academia and civil society to help ensure we address the gap on good quality and comparable data on disability. We also encourage the use of disability disaggregated data alongside other equity variables to understand and address the intersectionality of marginalisation, to ensure development progress that truly leaves no one behind.

Further information

Additional resources, including policy briefs, presentations and reports on disability disaggregated data, are available at: **www.sightsavers.org/everybodycounts**

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Beneficiaries in our Inclusive Eye Health project in Nampula Province, Mozambique waiting for an ambulance.

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We work with partners
in developing countries to
eliminate avoidable blindness
and promote equal opportunities
for people with disabilities.

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