Everybody counts

Sightsavers' disability data disaggregation project

August 2017

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Background

The lack of comparable data on disability remains a critical development issue. Without better, more accurate and comparable data on disability it will not be possible to accurately measure development progress and truly ensure no one is left behind. This briefing shares Sightsavers' experience of collecting disability disaggregated data using the Washington Group Short Set of Questions. Our findings are allowing us to develop an organisational approach to collecting better data on disability and improving the accessibility of our programmes as a result. We are sharing our experiences and encouraging other development actors to collect and disaggregate data to ensure inclusive development is realised in practice.

There are an estimated one billion people with disabilities across the world[1], yet there remains a lack of accurate and comparable data on disability globally. This lack of data often means decisions are made that reinforce existing inequalities, as governments and decision-makers allocate resources in a way that excludes people with disabilities. This is further compounded within international development programmes; as many organisations do not collect data on disability it is impossible to know how and if people with disabilities are participating.

The 2030 Agenda for Sustainable Development has set out to address exclusion and ensure no one is left behind[2]. The Agenda references disability specifically in five goals and seven targets, and commits countries to disaggregating data by disability across a number of indicators[3]. Better, more accurate data on people with disabilities – and on other people who experience exclusion – is required if Agenda 2030 is to deliver lasting change. Greater collaboration between governments, multilateral and donor agencies, and civil society is required to promote, collect, analyse and report better data on disability.

An ophthalmic clinical officer examining a patient at a cataract screening camp in Kasungu, Malawi.

Front cover image:

Data collectors taking notes at an eye screening camp at Karond Chauraha (Crossroad), Bhopal, India.

What we have done so far

Sightsavers has been disaggregating data by disability in a number of our health programmes. We want to understand whether people with disabilities are accessing eye health services, build the evidence base on how to disaggregate routine data by disability, and ultimately ensure all health services are accessible.

The Washington Group on Disability Statistics was formed by the UN Statistical Commission in order to facilitate the collection of comparable national-level disability data. A series of question sets have been designed to operationalise the International Classification of Functioning, Disability and Health (ICF) into national surveys and censuses[4]. We have been testing the Washington Group Short Set of Questions[5] (WGSS) – which focus on functional limitations – in a number of our programmes.

In **India** we integrated the WGSS and the Indian national census question on disability ('Are you disabled?') into an Urban Eye Health programme, and at vision centres, outreach camps and an NGO eye hospital. This pilot collected data on 24,518 patients over a 16-month period.

In **Tanzania** we used the WGSS in a neglected tropical disease (NTD) elimination programme, specifically integrating data collection into trachoma trichiasis (TT) camps. In this pilot we collected data on 1,439 patients who attended the camp over a four-month period.

In **Malawi** we integrated the WGSS into data collection systems at a TT camp in our Coordinated Approach to Community Health project. In this pilot, we also used The Equity Tool[6], which allowed us to disaggregate data by socio-economic status using an asset-based measure of wealth. We collected data on 545 patients over a six-day period.

A screening camp organised for people affected by the Bhopal Gas Tragedy at Khanugaon, Bhopal.

What the data has revealed

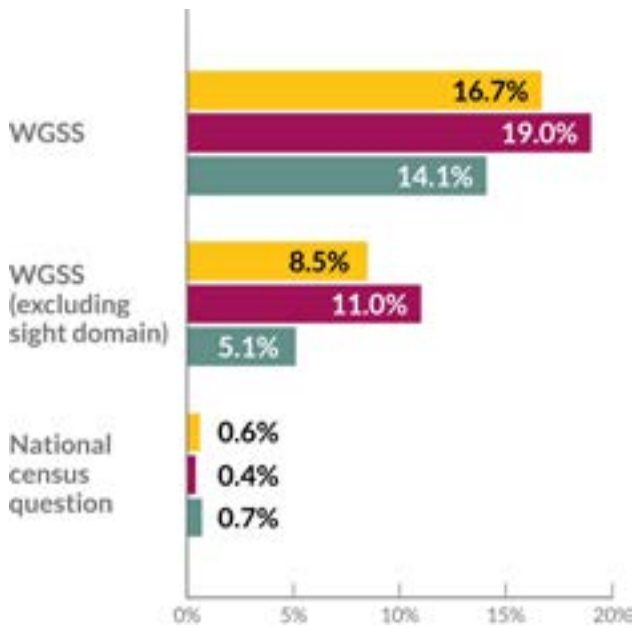Collecting disability disaggregated data has revealed a number of interesting findings.

In **India**, the value of using the WGSS for more accurate data was clearly demonstrated: 16.7 per cent of respondents identified as people with disabilities. Even excluding the sight domain – which we would expect to be high in our programmes – the prevalence was nearly 9 per cent. This compared to just 0.6 per cent of people who responded 'yes' to the national census question: 'Are you disabled?'.

Our data also showed that age was positively associated with disability, and that female patients had a greater likelihood of reporting functional limitations but a lower likelihood of self-identifying as people with disabilities than male respondents.
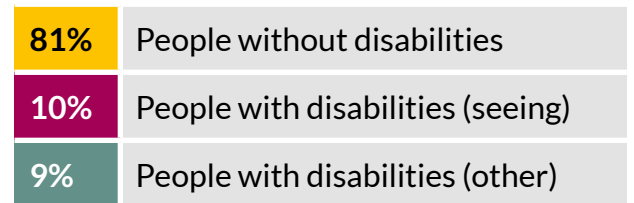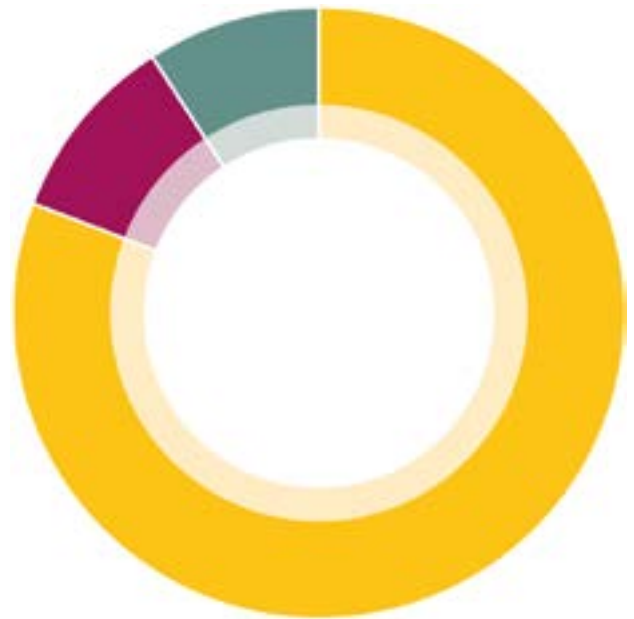
In **Tanzania**, our data also showed a high prevalence of people with disabilities attending NTD camps at 19.3 per cent. Our data also revealed that 10 per cent of people who attended TT camps had a wide range of functional limitations and needs that are not met by services offered at the camps. This suggests people were seeking other basic health services that are not readily available in the local community, and potentially reveals a lack of service availability in remote areas.

In **Malawi** data collected alongside The Equity Tool indicated the majority of patients were in the second wealthiest quintile (28 per cent), with the minority falling into the poorest (11 per cent). This shows that individuals who were attending the TT camps are relatively richer than the general population in Malawi. This highlights that the outreach services may not always be reaching the poorest and most excluded people. Although the numbers were small, the data also indicated that people in the lower wealth quintiles were more likely to report being 'disabled' than wealthier people.
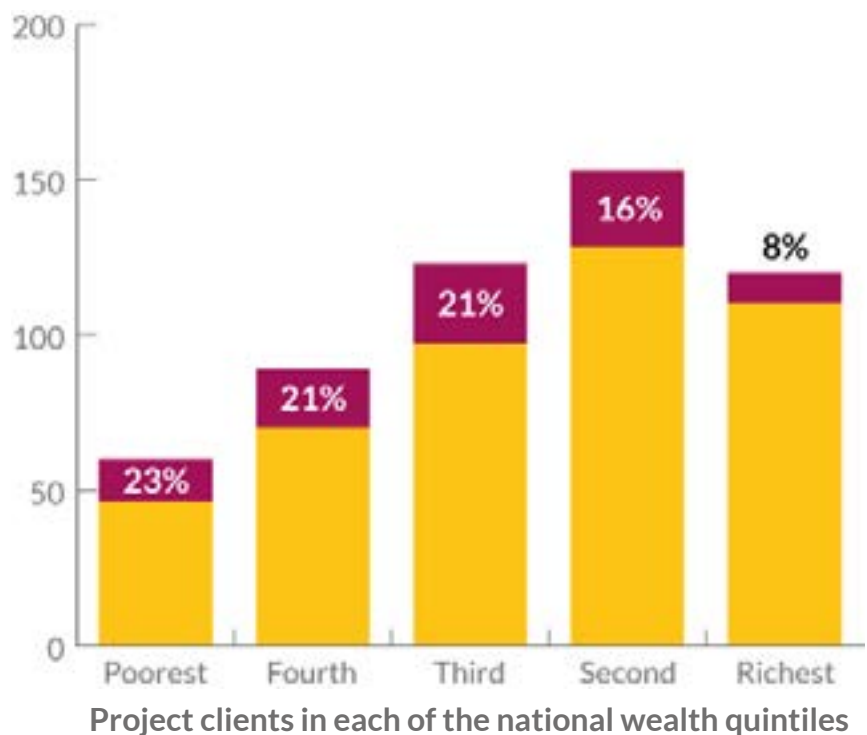
India – Prevalence using the WGSS and national census question

WGSS	16.7% / 19.0% / 14.1%
WGSS (excluding sight domain)	8.5% / 11.0% / 5.1%
National census question	0.6% / 0.4% / 0.7%

0% 5% 10% 15% 20%

🟡	Total
🟣	Women
🟢	Men

Tanzania – Prevalence of disability at registration

81%	People without disabilities
10%	People with disabilities (seeing)
9%	People with disabilities (other)

Malawi – Project clients in each of the national wealth quintiles

🟡	Number of clients
🟣	Prevalence of disability

Project clients in each of the national wealth quintiles

Poorest 23% · Fourth 21% · Third 21% · Second 16% · Richest 8%

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Ophthalmic clinical officers giving a talk on eye health during screening camps in Kasungu, Malawi.

How we are using our data

The information we have collated has informed a number of decisions about our programmes and how we intend to collect further disability disaggregated data in future.

In **India**, our pilot has evolved into an Inclusive Eye Health project[7]. Collecting data on disability was always the first step in a process towards full inclusion. Our partners wanted to continue collecting disability disaggregated data, but in an improved way, building on their experience and conducting further analysis where required. The project team are now exploring better technology solutions and a more effective Health Management Information System, and including more exit interviews and learning from evaluations. They will also: undertake research to assess barriers for women accessing health care facilities; conduct accessibility audits; include training for staff on gender mainstreaming and disability inclusion; connect with other service providers and establish referral mechanisms; improve the accessibility of information, education and communication materials; and conduct awareness raising activities to improve public awareness of the rights of people with disabilities and other marginalised groups.

In **Tanzania** qualitative information collected alongside the WGSS confirmed that due to the context in rural Tanzania, people with disabilities were attending outreach camps seeking general health services. Health workers wanted to implement a more coordinated approach to eye health in order to meet the health needs of the rural community. This led to health workers identifying needs in each village, and targeting interventions accordingly – for example, collecting medicines on the way to a camp when health workers know a village is far from a local health facility, and providing other minor treatments and surgeries that they are equipped to deliver. As in India, a referral mechanism with nearby health facilities has also been established to ensure a more coordinated approach.

In **Malawi** we learnt that using the WGSS alongside The Equity Tool was possible and useful, and were able to gain a deeper insight in to the relationship between poverty and disability affecting people accessing our programmes.

What we are going to do next

We will continue to analyse data from all of our programmes, and adapt and improve our approach based on what we are learning. We are currently testing the WGSS in a number of other contexts, including household surveys to measure political participation in Cameroon and Senegal and treatment coverage surveys for NTDs in the Democratic Republic of Congo, Guinea Bissau, Nigeria and Uganda. We are also testing the Washington Group Child Functioning module[8] in Malawi.

Patients with disabilities speaking to data collectors at an eye screening camp at Govindpura, Bhopal.

Our experience so far has also allowed us to consider how we can better integrate disability disaggregated data across other areas of our work.

Given what we are discovering and our areas of expertise, we plan to:

- explore incorporating disability disaggregated data into other health programmes, to allow us to assess prevalence, identify individuals and populations in need and ultimately ensure health services are accessible.

- continue to test incorporating the WGSS in population-based surveys as a tool for disaggregating the results by disability, including RAABs and NTD coverage surveys.

- continue to explore how the WGSS can be used in a complementary way with other tools to better understand the multi-dimensional nature of exclusion, for example wealth equity assessment tools. This will give us a better, more rounded insight, that allows us to collect and analyse disability, gender, age, and wealth data to assess which population groups are accessing services and identify individuals and populations most in need.

An ophthalmic clinical officer sensitising patients on the E-Chart at a screening camp in Kasungu, Malawi.

Recommendations

The WGSS have provided a critical first step to improving the accessibility of our programmes, and our experience demonstrates that they are an appropriate tool for collecting disability disaggregated data in health programmes.

However, it is critical to acknowledge that simply collecting data will not change anything: there must be a plan for analysing and acting on the data.

We would encourage other actors to disaggregate their data by disability, and recommend:

- developing clear objectives for why data is being disaggregated.

- planning how data collected will be analysed and used to inform decision-making.

- including contextual sensitisation and training on disability, and on the Washington Group questions, along with translating questionnaires and introductions, and testing them during training sessions. These are essential requirements to ensure data is valid.

- 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.

- collecting the experience of data collectors through workshops and reviewing the approach every six months based on evidence.

Our experience has shown us that disaggregating data by disability is not only possible, it also has the potential to be transformational. The process of collecting data on disability helps raise awareness and gets people talking about their health needs, ensures health workers prioritise the rights of people with disabilities, and helps sensitise policymakers and the wider community on the importance of accessible health services and disability-inclusive practice.

For the 2030 Agenda to have the impact that is required, transformational change is essential. We hope that by sharing our experience we can contribute to the evidence base, help drive the collection of better, more accurate data, and ultimately ensure that everybody counts.

Additional sources including policy briefs, presentations, and baseline and evaluation reports from our work on disability disaggregated data are available at:

www.sightsavers.org/everybodycounts

For further information please contact:

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References

1. World Health Organisation and World Bank (2011) World Report on Disability www.who.int/disabilities/world_report/2011/report.pdf [Back]

2. United Nations (2015) Transforming Our World: The 2030 Agenda for Sustainable Development sustainabledevelopment.un.org/content/documents/21252030%20Agenda%20for%20Sustainable%20Development%20web.pdf [Back]

3. United Nations (2016) Report of the Inter-Agency and Expert Group on Sustainable Development Goal Indicators sustainabledevelopment.un.org/content/documents/11803Official-List-of-Proposed-SDG-Indicators.pdf [Back]

4. Washington Group on Disability Statistics: www.washingtongroup-disability.com [Back]

5. Washington Group Short Set of Questions: www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions [Back]

6. The Equity Tool: www.equitytool.org [Back]

7. Sightsavers' approach to Inclusive Eye Health: www.sightsavers.org/inclusive-health [Back]

8. Washington Group Child Functioning Question Sets: www.washingtongroup-disability.com/washington-group-question-sets/child-disability [Back]

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in developing countries to
eliminate avoidable blindness
and promote equal opportunities
for people with disabilities

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