Everybody counts

Lessons from Sightsavers' disability data disaggregation project

October 2015

Background

There is an acknowledged shortage of accurate data when it comes to measuring the participation of people with disabilities in development programmes. Sightsavers is testing the disaggregation of data in an attempt to learn how this can be done effectively. We are using the Washington Group short set of questions[1] in two programmes in India and Tanzania. We're finding out what works – and what doesn't – and developing an organisational approach to collecting disability disaggregated data in our health programmes. These findings will allow us to evaluate and improve the accessibility of our own programmes, but also more broadly to contribute to the debate on how best to collect data on the inclusion of people with disabilities, as a step towards their greater inclusion in development programmes.

In order to realise the promise of the Sustainable Development Goals (SDGs) to 'leave no one behind'[2] more data on current and future access by people with disabilities is required.

This includes the seven SDG targets specifically referencing disability, the six targets that focus on persons in vulnerable situations and the two that relate to non-discrimination. We know it will take countries time to prepare new collection tools, and incorporate disability-indicators, but believe statisticians and programme implementers should include the Washington Group short set of questions in census, household and programme surveys. This pilot is designed to assist and inform that process.

The Hindi version of the questionnaire being used in Sightsavers' Urban Slum Eye Care Programme in Bhopal

[1] Washington Group on Disability Statistics. Recommended Short Set of Questions on Disability **http://www.cdc.gov/nchs/washington_group/wg_questions.htm**

[2] UN. Transforming our world: the 2030 Agenda for Sustainable Development **https://sustainabledevelopment.un.org/post2015/transformingourworld**

About our project

The Washington Group's short set of questions focus on functional difficulties and were designed to operationalise the World Health Organisation's (WHO) International Classification of Functioning into data systems.

We are using these in two programmes, selected for their geographical and thematic variety and opportunities to use new technology. The programmes are the Madhya Pradesh Urban Slum Eye Care Programme in Bhopal, India and the Neglected Tropical Diseases Programme in Ruvuma, Tanzania.

In India, data collection is incorporated into all collection tools at the points where a patient's demographic data is collected. An electronic health management information system has provided an opportunity for testing data disaggregation electronically as well as using a paper based system. The programme in Tanzania involves surgical camps in rural areas where health workers collect data on paper forms.

Data collectors test using the Washington Group questions out in the community in Bhopal

What we have learnt

Through our project we have identified a number of barriers that can prevent people from engaging with providing and collecting data on disability.

Negative attitudes and **stigma** can prevent people from answering questions or lead to prejudice in those asking the questions. Discussions with local disability organisations are critical to understand specific contextual and cultural issues. Disability is a concept highly dependent on contextual and cultural factors, so sensitisation on disability and the Washington Group questions in the relevant local language is essential. This helped change negative attitudes of staff towards patients with disabilities.

"I am seeing people like R. who said that he never used to respect people but now when someone with a disability comes, he gets up and helps them"
Programme Manager, India

It is crucial for people to know **why data is being collected**. We found patients are much more inclined to respond to a questionnaire when they know why they are being asked questions, so we added a short introduction.

Translation into local languages can be difficult. This was challenging in both countries, and suggests significant work is required to design translated surveys that apply the same concepts in different countries.

"People in this region are from Ndendeule and Makua tribes…**but Makua is very difficult to understand, it requires finding a person that can elaborate in their language."**
Programme Manager, Tanzania

Results depend on the **questions asked and definitions** used. In India, using the Washington Group recommended definition of a person with disability as 'everyone with at least one domain that is coded as a lot of difficulty or cannot do it at all' appears to show barriers to people with disabilities accessing the programme. But there is also a significant difference between the data collected using these questions and results from the national census question (Are you DISABLED? Yes/No). Using the Washington Group questions therefore may result in a sharp elevation in the number of people with disabilities in comparison to those, including governments, applying more binary definitions of disability. While this may lead to a more accurate reflection of the extent to which programmes need to think of accessibility and inclusion, it may also affect people's willingness to use this methodology, particularly where the

assumptions (with little evidence) are of inclusion meaning additional costs.

To be effectively used, ongoing **training of staff** and the involvement of management levels is critical to foster a sense of shared ownership, and to build understanding. Consideration needs to be given to the integration of data collection into existing job roles, as in India it has been challenging for vision centre assistants. Identifying challenges and adapting approaches based on experience, through regular review with data collectors, is essential.

Where the data is collected must also be considered. Busy clinic reception areas do not allow for privacy, and data collectors can spend more time with patients in small centres than busy hospitals, which can affect quality of data. Young people who do not have disabilities can also get irritated by the questions, but those with disabilities, however, can respond positively to being asked.

Asking the questions also **raises expectations**. Staff have become sensitive to disability-issues and are keen to do more, whilst patients with disabilities are stimulated to find out additional information and ask about services. This has led to data collectors needing to know more about services they can refer to. Various unexpected referral initiatives have been reported

Patients wait to access outreach camps in Tanzania

as a direct result of the pilot and we have realised referrals to other services need to be integrated into future projects.

People can view the collection of this data as an extra burden or cost – but including data disaggregation from the start of a project can ease these concerns. Where projects already exist, integrating data collection into existing practices **improves efficiency** and positive engagement. Electronic formats should be favoured when they can be easily adapted.

It is critical that **ownership** is taken by health workers, policymakers and community leaders. Policymakers and management cadres need to understand the benefits of disaggregation, what the data can tell them and how it can support their work. Project managers and partners expect data to inform decision making and, simply by being asked questions, respondent's expectations are raised. Collected data must be used in order to make the process meaningful.

"You also need to look at the data, analyse it and use it. Just collecting data will not bring any change."
Country Director, India

National policies to collect data on all citizens would help people understand what data can tell them about their communities, the services available and their broader rights.

Data collectors and partners test using the Washington Group questions outside a school in Bhopal

Recommendations

Data disaggregation is possible, with the right planning, systems and flexibility. We recommend:

- Including contextual sensitisation and training on disability and the Washington Group questions in local languages.

- Translating questionnaires and introductions and testing them during training sessions.

- Adapting all training sessions to the local context and in line with national definitions of disability.

- Limiting references to disability, instead referring to difficulty in functioning to reinforce the link between accessibility and functional limitations.

- Developing a clear advocacy plan at the outset to make use of the data, engaging policymakers and promoting the project to government.

- Conducting refresher sessions quarterly to maintain quality.

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

Inclusion is no easy task, and some of the challenges we have encountered identify barriers government and development agencies need to overcome to ensure all people can access services – and be counted. Collecting better disability data will be critical to ensuring the SDGs have a genuinely lasting impact for some of the poorest people across the world. We hope that by sharing our learning, we can contribute to meeting this challenge, and support others to do the same.

Additional sources

Sightsavers (2014) Disability Disaggregation of Data – Baseline Report. Available at: http://www.sightsavers.org/wp-content/uploads/2015/09/Sightsavers-Baseline-Report-Disability-Disaggregation-of-Data.pdf

Sightsavers (2015) Disability Disaggregation Project – India Mid-Term Review Report. Available at: http://www.sightsavers.org/wp-content/uploads/2015/09/Sightsavers-Disability-Disaggregation-India-MTR_External.pdf

More information on the Washington Group on Disability Statistics. Available at: http://www.cdc.gov/nchs/washington_group.htm

For further information contact fsmith@sightsavers.org

Sightsavers

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

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