# Sightsavers Inclusive Data Charter: Action Plan

## Introduction

The 2030 Agenda for Sustainable Development, adopted by all world leaders, made the commitment to Leave No One Behind. In order to meet this promise there is an acknowledgement that the data used to measure progress must be disaggregated. At present very little data are routinely disaggregated.

> *SDG Target 17.18: By 2020, enhance capacity-building support to developing countries, including for least developed countries and small island developing States, to increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts*

This document outlines Sightsavers' commitment to the Inclusive Data Charter, and in recognition of that commitment it outlines a number of actions that we are promising to achieve in order to realise the vision and principles of the Charter which in turn will support the achievement of Leave No One Behind and Agenda 2030.

This Inclusive Data Charter Action Plan builds on the work that we have been implementing over the last few years. It solidifies our commitment to the collection and use of inclusive and disaggregated data, and commits us to continuing to share our evidence and work with others to improve the international development system on inclusive data.

In order to support the Inclusive Data Charter we are accelerating our efforts and being more ambitious in our actions. We are disaggregating more of our project data, by more variables. We are investigating how we can ensure that disaggregation by sex, age, disability, wealth and location are integrated in to research, monitoring and evaluation systems and processes.

We are supporting global efforts by working with a variety of governments and other organisations within the Global Partnership for Sustainable Development Data (GPSDD). We are advocating with governments to encourage the integration of data disaggregation in to Health Management Information Systems, Education Management Information Systems, and other systems.

This Action Plan is a fluid document and will be reviewed, revised, and updated annually.

# Inclusive Data Charter

Sightsavers was involved in the development of the Charter and formally signed up in July 2018. All of our work on data disaggregation is in line with the Charter's principles, and we have indicated below how our actions are linked to specific principles.

## Principle One – All populations must be included in the data

We can only achieve the "leave no one behind" goal by empowering the furthest behind. This means ensuring their voices are heard and their experiences are represented through data and analytics. We need to acknowledge all people, make them visible in the data to understand their lives, and include them in the development process.

## Principle Two - All data should, wherever possible, be disaggregated in order to accurately describe all populations

We recognize that data should be disaggregated by sex, age, geographic location, and disability status and, where possible, by income, race, ethnicity, migratory status, and other characteristics relevant in national contexts.

## Principle Three - Data should be drawn from all available sources

We recognize the need to make high-quality, timely data from official and non-official sources accessible, and that these should include new data sources, where consistent with internationally accepted statistical standards.

## Principle Four - Those responsible for the collection of data and production of statistics must be accountable

We will balance the principles of transparency - maximizing the availability of disaggregated data – confidentiality, and privacy to ensure personal data is not abused, misused, or putting anyone at risk of identification or discrimination, in accordance with national laws and the Fundamental Principles of Official Statistics.

## Principle Five - Human and technical capacity to collect, analyse, and use disaggregated data must be improved, including through adequate and sustainable financing.

We recognize that collecting and analysing disaggregated data needs specific skills and these must be built. We recognize the need to finance data collection, analysis, and use appropriately and sustainably so that high-quality data can be collected and used by governments as well as by businesses, civil society, and citizens.

# Current work and commitments

**Current work**
Sightsavers routinely disaggregates programme data by **sex and age** in order to monitor whether the health programmes we support are reaching the population in

an equitable manner. We have been focusing more on the analysis and use of this data, and using software such as PowerBI it is now possible for us to see sex and age disaggregated performance against targets on a quarterly basis globally, by country, by project and by indicator.

This level of analysis has led to changes in the way we set targets, and identified where there are gaps in programme implementation. For example, we know that 63% of cataract cases are in women, 37% in men, yet when we analysed the cataract rate in our programmes we found that we have consistently reached an equal amount of men and women (50:50) which is well below the global prevalence of 63%. As a result our country offices are more closely monitoring their sex disaggregated performance, identifying country specific cataract prevalence by gender data or using the global average of 63% female and setting targets accordingly. Countries are then identifying where they are not meeting this target and looking to develop new approaches to close the gaps while continuing to monitor the impact.

Over the last few years, Sightsavers has also been testing approaches to disaggregating data by **disability and economic status** in a number of programmes across Africa and Asia, enabling us to analyse the relationship between poverty and disability in relation to people accessing health, education and other programmes.

Sightsavers piloted the use of the Washington Group Short Set (WGSS) of questions on disability in an urban eye health project in India, which led to the development of an inclusive eye health programme. We have also tested the WGSS in data collection at Trachoma Trichiasis (TT) camps in Tanzania.  We have tested other approaches to disaggregating our data by disability, including integrating the WGSS and the EquityTool (ET) into a World Health Organization (WHO) approved population-based eye health survey methodology (the Rapid Assessment of Avoidable Blindness or RAAB tool). This took place in Tanzania and allowed us to investigate how wealth and disability interplay with access to health services in our programme districts.

In Ghana, we collected disability data through the mass drug administration (MDA) process within a Neglected Tropical Disease (NTD) programme. We have also tested using the WGSS and ET in treatment coverage surveys for NTDs in Nigeria, Guinea Bissau, Uganda, and DRC. In Malawi we used the Washington Group Child Functioning Module in early childhood education centres with young children and their parents in Malawi. In Senegal and Cameroon we used the WGSS in a household survey in order to measure the level of political participation of adults in national and local elections. We have also been testing approaches and tools to support the analysis and interpretation of the data by non-statisticians, such as Power BI. Power BI is software in which you can take quantitative data and create interactive charts, graphs and other data visualisations.  Power BI gives project staff the ability to analyse their data and enhance their project management practices as well as providing country, programme and organisational overviews of performance and aiding in project design.

We have also been working more on disaggregation our data by **location**, and in particular have been improving our core systems to allow for the collection and

reporting on data disaggregated in this way. Our Programme Portal currently disaggregates data by sex/age, but we are currently adapting this to a district model. Ultimately all our outputs will be available disaggregated by location be that a district, facility, or school and fed into a geographical information system (GIS) for precision spatial analytics and data modelling.

Sightsavers has **disseminated key learning** from our data disaggregation pilots widely, including with a number of UN bodies. We continue to work with the Washington Group, UNICEF, GPSDD and others in further developing this work.  We share existing and new evidence from our programmes and our data disaggregation work with DFID country offices and can co-ordinate with other NGOs (both disability and other sector focussed) to share experience and knowledge of working on inclusion in country.

**What we've done so far**
- **Sex and age** – we have been disaggregating programme data by sex and age for a number of years. Our focus is now on the analysis and use of this data. Data is summarized and made available through PowerBI for more detailed analysis, which is allowing country offices to monitor their sex and age disaggregated data and make changes to their approaches to fill gaps where necessary, for example:
    - In our Coordinated approach to Community Health (CATCH) programme we found that we were reaching fewer women than men with our eye health services, as a result we implemented a number of initiatives such as providing counselling to enhance awareness and rights messaging to females and other disadvantaged groups; using video clips of women who have successfully gone through surgery to encourage other women; and providing services free of charge hence making it easier for women who might not have any resources.

- **Disability**:
    - India Urban Eye Health Programme – collected WGSS at registration at central hospital and outreach
    - Integrated WGSS into data collection at Trachoma Trichiasis (TT) camps in Tanzania
    - In Ghana, collected disability data using WGSS in the MDA process, with Community Directed Distributors (CDDs) asking the questions.
    - Piloted using the Washington Group Child Functioning Module in early childhood education centres with young children aged 2-6, in Malawi

- **Disability and Economic Status**:
    - Included both the ET and WGSS in a population based survey in Singida, Tanzania, which has allowed us to investigate how wealth and disability interplay with access to health services in our programme districts.
    - Integrated WGSS and ET into data collection systems at TT camps in Malawi
    - Tested using WGSS and ET in treatment coverage surveys for NTDs in Nigeria, Guinea Bissau, Uganda, and DRC
    - Integrated WGSS and ET in a household survey in Pakistan

- In Senegal and Cameroon we used the WGSS and ET in a household survey in order to measure the level of political participation of adults in national and local elections, and in local decision-making institutions and political parties.

- **Location**:
  - The baseline patient survey for the Indian Sunderbans was analysed in a GIS, and a geographic health management information structure developed which attributes coordinate reference points to vision centre patient records. This data is imported into a GIS to facilitate geographically-informed coverage analysis and routine management oversight.  In addition the endline survey (June / July 2018) will also capture WGSS and ET data.
  - The District Elimination Timeline Tracker (DETT) initiative aims to monitor our NTD work with greater precision - at a district level. We are currently building our district data repository, which has included the disaggregation by district of all MDA and TT surgical outputs for 2017.
  - CATCH - data collected by mobile devices from each outreach site in Kenya and Uganda is presented in aggregated and location-specific PowerBI dashboards.
  - A location specific PowerBI dashboard has been developed for Irish Aid reporting in Senegal

**Our commitment to data disaggregation**

1) We will 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.

2) We will continue to work with the Washington Group to test new question sets and support ongoing work and advocacy for using the Washington Group Short Set of Disability Questions.

3) We will work to ensure the systematic inclusion of disaggregated data in our project systems and monitoring, and ensure that data is analysed and used to inform and improve programme implementation and policy.

4) We will continue to collect, report, analyse, and use data on age, disability, sex, economic status, and location, and sharing tools, guidance and learning with National Statistics Offices, ministries and civil society partners.

5) We will influence governments to collect better data to inform decision making and allocation of resources that deliver better policy and development outcomes for those at risk of being left behind

6) We will work in collaboration with other INGOs and donor agencies to share learning and build knowledge.

7) We are committed to increasing the capacity of Sightsavers staff and partners to incorporate data disaggregation into their work

These commitments are outlined in more detail in the Action Plan below.

# Data disaggregation plan: GET – USE - SHARE

This plan focuses on three important areas, getting data, using data, and sharing data. Actions are structured around these three areas.

**GET** –
- Where relevant we will disaggregate our programme indicators by sex, age, disability, economic status, and location.
- We will use standardised tools to collect this data.
- We will test new data collection methodologies where appropriate.

**USE** –
- We will increase the capacity of our staff and partners to disaggregate data and use this data to improve programme interventions.
- We will continue to use software such as PowerBI to support the analysis of data, and enhance project management.
- We will use evidence from our programmes to influence others.

**SHARE –**
- We will share learning from our programmes, through policy briefs, research reports, programme evaluations and through our website
- We will share evidence and learning at relevant conferences, events, workshops and forums.

| Objective | Actions | Link to IDC Principle |
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| 1. Increase capacity of Sightsavers staff and partners to incorporate data disaggregation in to their work | a. Develop a repository of guidance sheets for staff on disability data disaggregation (**GET + USE + SHARE**) | Principle five |
| | b. Webinars for staff and others (**USE + SHARE**) | Principle five |
| | c. Learning seminars on data disaggregation (**SHARE**) | Principle five |

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| 2. Systematic inclusion of disaggregated data in project systems and monitoring. | a. Disability disaggregated data is collected, analyzed and used to inform programme improvements through routine programme monitoring and evaluation activities (**GET + USE + SHARE**). Piloted in:<br>   i. Inclusive Eye Health programmes in Mozambique<br>   ii. Inclusive Eye Health programme in Pakistan and Bangladesh | |
| | b. Learning review of the integration of disability data collection and disaggregation in to routine monitoring and evaluation processes | |
| | c. Systematic inclusion of disaggregated data in project systems such as Project Reporting and Oversight, Project Design Process, Start Up and Inception Processes, Baseline and Evaluation processes (**USE**) | |
| 3. Continue to collect, report, analyse, and use data on age, disability, sex, economic status, and location data where relevant, and contribute to evidence base on how to. | a. Develop guidance on when useful to disaggregate by one / several of the following: age, sex, disability, economic status, location (**USE**) | Principle two |
| | b. Develop a guide that will outline what mHealth/spatial mapping possibilities there exist for new projects together with an indicative budget for such activities (**GET**). | |
| | c. Continue to incorporate the WGSS and EquityTool / Poverty Scorecard in geo-referenced population-based surveys (**GET**):<br>1) Rapid Assessment of Avoidable Blindness survey in Mozambique which will include sex, age, economic status and disability as disaggregants<br>2) Indian Sunderbans we will conduct a population level eye health survey which will include sex, age, economic status, disability as disaggregants. | |

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| | 3) 4 RAABs through the UK Aid Match programme which will include sex, age, economic status and disability. | |
| | d. Continue to explore how the WGSS can be used in a complementary way with other tools | |
| | e. Continue to test other tools for disaggregation, such as other Washington Group Tools; and for data collection, such as the WHO Model Disability Survey (**GET + USE**) | |
| | f. Contribute to the evidence base by publishing research findings in relevant academic journals and making presentations at conferences (**SHARE**) | |
| 4. Meet all data disaggregation commitments in new funding streams should they be successful, such as UK Aid Connect, DID, Audacious | a. Apply the WGSS across programme interventions and use rigorous data analysis to inform national and international advocacy messaging, supporting people with disabilities, the private sector and civil society to advocate for systematic collection of disability data (**USE + SHARE**) | |
| | b. Evaluate and document key innovations in the programmes, capturing key lessons, insights, impacts and evidence that can help them to be taken to scale and to be disseminated widely (**USE**). | |
| | c. Explore piloting the ILO/Washington Group Disability Module for Labour Force Surveys (**GET**). | |
| 5. Develop and share learning with NSO, ministry and CSO partners | a. Work in partnership with health, education and other relevant ministry and service delivery partners, in the design, implementation and analysis of data disaggregation activities | |

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| | b. Publish reports & policy briefs with clear recommendations (**SHARE**) | |
| | c. Work closely with other CSO data disaggregation experts, for example Leonard Cheshire Disability International Development Centre on storing, analysing and disseminating disability disaggregation information (**USE + SHARE**) | |
| | d. Keep up to date the web page (**SHARE**): www.sightsavers.org/everybodycounts | |
| 6. Provide evidence to support implementation of the 2030 Agenda | a. Contribute to work of the UN Expert Group on data disaggregation by providing evidence on both methodology and results (**USE + SHARE**). | |
| | b. Contribute to work of UN Network on Monitoring and Evaluation on Disability and Inclusive Development (**USE + SHARE**) | |
| | c. Work closely with the International Disability Alliance (IDA), International Disability and Development Consortium (IDDC), and others to continue to make the case for disaggregation by disability in the above fora and others, in the official statistics for Agenda 2030. (**USE**) | |
| | d. Continue to play a leading role in the GPSDD Task Team, alongside GPSDD and DFID (**USE + SHARE**) | |
| 7. Partnerships / working in collaboration | a. Continuing to work with the Washington Group to test new modules and keep informed of existing work using WGSS (**GET + USE**). | |

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| | b. Working with other INGOs in the sector e.g. Humanity and Inclusion (HI), Leonard Cheshire Disability (LCD), Light for the World (LFTW) to share learning and build knowledge (**USE + SHARE**) | |
| | c. Working with disability movement in all data projects focusing on disability disaggregation, specifically IDA. (**USE + SHARE**) | |
| 8. Testing new technologies for capturing and managing data to improve accuracy and speed of data collection and analysis | a. mHealth – testing smartphone data collection tools, such as CommCare and Greenmash, in order that data is collected, collated and transmitted 'live' and reducing the potential for errors (**GET + USE**) | Principle three |
| | b. Biometrics – exploring how thumb/finger print scanners can help with tracking patient referrals and service uptake (**GET + USE**) | Principle three |